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THE UNIVERSITY OF ALBERTA

AN EXPLORATION OF MATERNAL ATTACHMENT TO THE PRETERM INFANT

by

BARBARA BRADY-FRYER

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE

OF MASTER OF NURSING

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EDMONTON, ALBERTA

SPRING, 1988

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled AN EXPLORATION OF MATERNAL ATTACHMENT TO THE PRETERM INFANT submitted by BARBARA BRADY-FRYER in partial fulfilment of the requirements for the degree of MASTER OF NURSING.

Peggy Anne Field
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Iris E. Campbell

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Date 18 April 1988

DEDICATION

This work is lovingly dedicated to my husband

BRIAN

my best friend and greatest supporter

ABSTRACT

This study was conducted in order to investigate and depict mother's experiences of attachment to their newly born, hospitalized, preterm infants. The research questions which guided the inquiry were: 1) how do mothers of newly born, hospitalized, preterm infants describe their attachments to their infants at particular points in time? 2) how do mothers of newly born, hospitalized, preterm infants describe their attachments to their infants over time? 3) what factors do mothers describe as influencing or affecting their attachment to their newly born, hospitalized, preterm infant?

"Attachment" was not defined prior to data collection. Rather, the term was assumed to have a familiar meaning to study informants, that is, a shared cultural meaning among the members of the study group.

Six multiparous women whose newly born preterm infants were hospitalized in a Neonatal Intensive Care Unit (NICU) were selected for the study. All mothers had previously achieved at least one fullterm pregnancy, and the current pregnancy marked subject's first experience with preterm labor and delivery. Study informants were involved in stable marital relationships and in each case were living with the preterm infant's natural father and siblings.

Four of the pregnancies that produced the preterm infants were planned and two were not. Five of the

pregnancies were for a single fetus and one was for twins. The preterm infant group was comprised of four males and three females (one set female twins), born between 26 and 34 weeks gestation. The infants born to study subjects had varying degrees of postnatal complications, and hospitalizations ranged from 23 to 109 days in length. Each study mother was able to visit her infant regularly during his or her hospitalization. All infants survived the neonatal period and were discharged to home from the NICU.

A qualitative approach to data collection and analysis, specifically, grounded theory method (Glaser & Strauss, 1967), was employed. Data were collected in a series of unstructured interviews with each informant. The interviews were begun at approximately two weeks postbirth and continued until the preterm infant's discharge from hospital. In total, 17 interviews were conducted.

Utilizing the constant comparative method (Glaser & Strauss, 1967), the basic social process of "forging a role" was identified: a process through which study subjects built personal identities as mothers of newly born, hospitalized, preterm infants. The drive to define this identity arose from each mother's need to continue the attachment relationship she had begun with her infant during pregnancy. For study mothers, forging a role provided access to the extension and further development of her attachment relationship with her preterm infant in the postpartum period.

The results of this study negate findings from much of the previously reported attachment research which assumed an immediate postbirth beginning for the mother-infant relationship. On the other hand, the results of the study support the concept of the development of a mothering role, which, for study mothers, was subject to the constraints placed by preterm delivery and the illness and hospitalization of the infant. Results also support that the mother's attachment relationship to her infant is a process beginning with her acceptance of the existence of the pregnancy, and continuing as an adaptable, dynamic process throughout the pregnancy and into the postpartum period.

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Chapter I

INTRODUCTION

Advances in medical knowledge, technique, and technology have revolutionized the field of neonatology over the past two decades. The medical and nursing care of many newborn preterm infants who would never have survived 15 years ago is now considered routine. The percentage of preterm infants who not only survive, but do so without major physical, emotional or intellectual deficits is growing. The time has long since past when preterm infants were treated as nonviable freaks, suitable for exhibit at sideshows and fairs (Klaus & Kennell, 1976).

The first center for preterm care opened as recently as 1923, at the Sarah Morris Hospital in Chicago. A review of the history of preterm care, which had its beginnings at institutions such as this, shows that the search for an ideal treatment regimen for these infants has been a difficult one, characterized by good intentions, sometimes with disastrous results. To cite one example, at the Sarah Morris, the preferred feeding method recommended a course of virtual starvation for low birthweight infants. This was done in order to avoid overfeeding, which, at the time, was believed to be a major cause of neonatal death (Goldberg & DiVitto, 1983). By today's standards such a plan for newborn care seems absurd and almost barbaric. However, despite the enormous knowledge deficit that existed at the time, the

general prognosis for preterm infants began to gradually improve once their physical care became hospital-based.

Unfortunately, the institutionalization of preterm infants had additional drawbacks. To prevent the spread of infection, as a rule these infants were isolated in the sterile, unstimulating environment of the neonatal nursery, and parents were not permitted contact with their infant until his discharge (Barnett, Leiderman, Grobstein, & Klaus, 1970; Klaus & Kennell, 1976). Although these measures were taken to protect the newborn, one can only speculate on the effect that this state of affairs must have had on developing parent-infant relationships.

By the late 1960's, due primarily to the pioneering work of two pediatricians, Marshall Klaus and John Kennell, the parental need for relationship with the newborn was beginning to be recognized and accommodated by health care providers. Fathers were allowed to attend hospital births, and both parents were being encouraged to spend as much time as they desired with their infant after birth and during the early postpartum period in hospital.

Concomitant with this general change in the philosophy of institutions towards family-centered perinatal care, the doors of the nurseries which cared for preterm infants were gradually being opened to admit parents into their infant's world. Indeed, many changes have occurred since the time when parents were not allowed contact with their hospitalized preterm newborn. Happily, as the preterm

infant's chances for life have improved, so have his chances for being valued and understood as a unique individual with special needs, characteristics, and capabilities.

Background of the Study

The process by which a mother forms a relationship with her child is only beginning to be understood, despite a vigorous multidisciplinary research effort and an enormous amount of literature produced on the topic. Work with mothers and their fullterm infants has provided only a basic conceptualization of the process of relationship formation, or attachment. Through examination of mothers' personal experiences, investigators have been able to describe attachment as a process, beginning during pregnancy and continuing in the postpartum period. Evidence exists which supports the concept of the mother's attachment to her infant evolving through her increasing awareness, both during pregnancy and after birth, of his unique characteristics and capabilities (Gottlieb, 1978; Rubin, 1977; Stainton, 1985a, 1985b). Contact with and caring for the newborn in the postpartum period facilitates the process, as does the infant's increasing responsiveness to mothering (Gottlieb, 1978; Stainton, 1985b).

Maternal attachment to the preterm infant has been less extensively examined. Investigators have maintained that there are associations between preterm birth, disturbed attachments, and subsequent infant maltreatment (Hunter,

Kilstrom, Kraybill, & Loda, 1978; Stern, 1973). However, the implications of interrupted pregnancy, newborn illness, maternal-infant separation, limited contact, and minimal maternal involvement in care for the development of the mother-preterm infant relationship are not understood.

Questions remain as to whether the institutional care provided preterm infants today facilitates the development of attachment relationships (Taylor & Hall, 1980). Enormous sums of money are invested in medical and nursing practice and research intended to preserve the lives of preterm infants. Health care professionals are now more likely to regard these "little miracles" as whole persons, with physical, emotional, and intellectual needs. They are also members of families, and the importance of treating them as such, despite the technologically oriented environment of neonatal intensive care, cannot be overemphasized.

While a basic conceptualization of the attachment process that occurs between mothers and their fullterm infants has been described, no understanding of the process as it occurs between mothers and their hospitalized preterm newborns has yet been reached. Therefore, in this study, the techniques of grounded theory (Glaser & Strauss, 1967) were employed to examine this process from the mother's point of view.

Purpose of the Study

The purpose of this study was to develop a basic conceptualization of the process of maternal attachment to a newly born, hospitalized, preterm infant. It was intended that the results of this research would broaden the knowledge available on maternal-infant attachment. In addition, it was intended that health care professionals would be able to use the results of this study to better plan their interventions to assist mothers to form attachment relationships with their hospitalized preterm infants.

Statement of the Problem and Research Questions

The problem was to elicit and describe mothers' perceptions and experiences of attachment to their newly born, hospitalized, preterm infants. The following research questions guided the investigative inquiry:

1) how do mothers of newly born, hospitalized, preterm infants describe their attachments to their infants at particular points in time?

2) how do mothers of newly born, hospitalized, preterm infants describe their attachments to their infants over time?

3) what factors do mothers describe as influencing or affecting their attachments to their newly born, hospitalized, preterm infants?

Definitions of Terms

attachment- There are many references to the term attachment present in both the professional and the lay

literature. Within this literature, the term is defined and used in a variety of ways. The intent of this research was to describe mothers' experiences of attachment to their newly born, hospitalized, preterm infants. Therefore, for this study, an emic, or personal perspective of the experience of attachment was required. Consequently, the term was not strictly defined in advance of data collection, or at any other point in the study. Rather, attachment was assumed to have a broad, colloquial meaning for each informant having to do with a maternal feeling of commitment to, or love for, her preterm infant.

preterm infant- an infant born at a gestational age of less than 37 weeks

multipara- a woman who has had one or more pregnancies resulting in viable offspring

role- the functions a person performs when occupying a particular characterization (position) within a particular social context (Shaw & Costanzo, 1970)

Significance of the Study

Nurses working in the neonatal intensive care area often become deeply involved for prolonged periods of time, with preterm patients and their families. These nurses are in a unique and powerful position, in which they are able to influence and assist the formation of relationships between mothers and their newly born, hospitalized, preterm infants. This investigative effort provides some insight into the

attachment experiences of mothers of hospitalized preterm infants, and will hopefully influence the steps of the nursing process and facilitate improved nursing care of these infants and their families.

Secondly, the results of this study serve to enlarge the existing general knowledge base on the process of maternal-infant attachment. Exploratory research such as this helps to establish a foundation and supplies the stimulus for further research work specifically in the area of mother-preterm infant attachment.

Finally, as a professional group, nurses are coming to a greater appreciation of the importance and benefits of the conduct and utilization of nursing research. However, they must recognize the different but essential contributions to nursing theory that both qualitative and quantitative investigations make. Studies such as this one, conducted from the emic perspective, provide an intimate, client-centered perspective of the phenomenon of interest. Nursing, as a human science, especially stands to benefit from the findings of this type of research. Hopefully, as more qualitative investigations are conducted, familiarity will foster acceptance of the method as a valid and essential technique in nursing research.

Chapter II

REVIEW OF THE LITERATURE

The mother-infant relationship has been at the center of a continuing debate and the focus of a dedicated research effort since the early 1960's. In the past, disturbances in this relationship have been associated with behavioral disorders of infancy and early childhood (Bowlby, 1973, 1977). Concerns about the consequences of maternal behavior for the intellectual, psychological, and physical development of the infant and child have heightened professional interest in the nature of the mother-infant tie. However, despite widespread interest and investigation in this topic area, controversies abound.

In this chapter, the literature available on the process of bonding or attachment for both fullterm and preterm infant-mother dyads will be summarized and compared. The restriction of the focus of this review to literature dealing with *mother-to-infant* bonding or attachment does not preclude an awareness on the part of the investigator of the literature addressing the issue of *infant-to-mother* bonding or attachment. Admittedly, it may not be advisable in a broader context to compartmentalize the dynamic, reciprocal interaction between a mother and her child into circumscribed units. However, as the purpose of this research was to elicit and describe the mother's experience of attachment to her newly born, hospitalized, preterm

infant, this literature review was focused and limited accordingly.

In this chapter, the numerous methodological issues and controversies associated with the body of bonding/attachment research are considered. The chapter also addresses parental responses to preterm birth, and maternal role acquisition during pregnancy.

Within the literature reviewed, the different but related terms of attachment and bonding were poorly defined and often used interchangeably. Usually, the term bonding referred to a rapidly occurring process of relationship formation between a mother and her newborn. Taking place very soon after birth, bonding was thought to be facilitated by close physical contact between the mother and infant. Certain maternal behaviors were hypothesized to be indicative of this unidirectional mother-to-infant tie, such as proximal touching, maintenance of eye contact, and maternal caressing of the infant (Klaus & Kennell, 1976).

The term attachment, on the other hand, was often but not always used in the literature to refer to the infant-to-mother tie that develops over the first year of life (Bowlby, 1958, 1969). Authors hypothesized that the nature of this relationship was influenced by the quality of mother-infant interaction over that first year, and that healthy attachment was evidenced by such infant behaviors as following mother, clinging to mother, and by separation protest (Ainsworth, 1969; Bowlby, 1977).

Unfortunately, the inconsistencies in the usage of these terms in the literature contribute to the shortcomings of this research effort as a whole. However, for the purpose of selection of reports for this review, the terms bonding and attachment were not defined. Rather, literature was selected and examined based on the author's expressed description of the purpose of the work. That is, literature purported to address mother-to-newborn relationship formation was included, regardless of the term used in the report to label the process.

The Mother to Infant Attachment Relationship

The existence of a warm, consistent, nurturing relationship between a mother and her infant is necessary for the healthy development of the child (Ainsworth, 1969; Bowlby, 1958; Campbell & Taylor, 1979; Klaus & Kennell, 1983). Interestingly, most studies on the development of mother-infant attachment relationships have been based on theory derived from subhuman animal studies in which the formation of specific, durable relationships had an essential biologic function in the preservation of the species (Ainsworth, 1969; Bowlby, 1977; Campbell & Taylor, 1979). Such studies gave rise to hypotheses about the existence of a critical, sensitive, or optimal period for human mother-to-infant relationship formation. Such hypotheses were popularized initially by the work of Klaus & Kennell (1976). The theories put forth by these two

pediatricians about the beneficial aspects of maternal bonding during the "critical" period after birth provided a line of inquiry for many of the research investigations which were to follow. They later observed that mothers of preterm infants behaved differently than mothers of fullterm infants when they returned to the follow-up clinic.

The bulk of the work on the bonding or attachment of mothers to their infants falls into two categories. In a small number of studies, investigators report on the mother's experiences of attachment to their infants. The majority of reports however, outline the investigator's examination and interpretation of maternal "attachment" behaviors in response to two experimental conditions: early and extended contact. A summary of the literature dealing with both fullterm and preterm infant-mother dyads follows.

Mother-Fullterm Infant Dyads

Maternal Experiences of Attachment

Attachment of mothers to their fullterm infants is initiated and experienced to varying degrees during pregnancy. Mothers-to-be have described a pleasurable awareness and interpretation of fetal behavior (Cranley, 1981; Stainton; 1985a, 1985b). Some mothers experience an intense, emotional investment in their unborn child (Leifer, 1980; Robson & Moss, 1970; Rubin, 1977; Stainton, 1985b). Pregnant women often imagine themselves in their role as mother, and name their child before birth (Cranley, 1981;

Rubin, 1975). Some authors have suggested that the strength of the expressed maternal bond to the unborn child may predict maternal behaviors and attitudes after birth (Leifer, 1980; Robson & Moss, 1970), but this has not been consistently found.

Attachment to the child in the postpartum period has been described by mothers as a slowly evolving process (Stainton, 1985b). Health and normalcy of the infant are of primary importance (Rubin, 1984). Despite their experiences with the fetus during pregnancy, most mothers initially perceive the newborn as an unknown entity, and this perception of anonymity drives the attachment process in the period after birth. Gottlieb (1978) likened attachment to an ongoing discovery during which the mother comes to know her infant by identifying his special characteristics and relating them to herself and to other family members. The newborn is gradually identified as a separate, unique person, and is claimed by the mother in a family and social context (Rubin, 1977). Contact with and caring for the infant facilitates the development of the attachment relationship, as does the infant's expanding repertoire of behavioral responses to mothering (Gottleib, 1978; Leifer, 1980; Robson & Moss, 1970; Rubin, 1977, 1984; Stainton, 1985b). The mother's knowledge of her infant and her pleasure in his acquaintance increase over time and stabilize the attachment relationship. The mother conceptualizes her role in relation to the infant through

her attachment to him (Rubin, 1984), and anticipates their future together with excitement (Gottlieb, 1978).

Maternal Attachment in Response to Experimental Conditions

Observations of maternal "attachment" behaviors occurring in response to two experimental conditions have been made in many investigations. The first experimental condition, that of early contact, usually consisted of opportunities for skin-to-skin contact between the mother and her infant very soon after birth. The second experimental condition, that of extended contact, usually consisted of opportunites for additional contact between mother and infant, that is, more than was permitted by normal routine during the postpartum hospital stay.

The argument that a link exists between the occurrence of either or both of these experimental conditions and healthy maternal bonding or attachment is based on the theory that contact after birth is necessary for the formation of the bond which provides the foundation for optimal future maternal behavior (Lamb, 1982). That this reasoning has been perceived as a persuasive argument is evidenced by the considerable effort which has been expended examining the effect of these two conditions (Ali & Lowry, 1981; Carter-Jessop, 1981; Curry, 1982; deChateau & Wiberg, 1977a, 1977b; Grossman, Thane, & Grossman, 1981; Hales, Lozoff, Sosa, & Kennell, 1977; Klaus, Jerauld, Kreger, McAlpine, Steffa, & Kennell, 1972; Klaus & Kennell, 1976;

Kontos, 1978; O'Connor, Sherrod, Sandler, & Vietze, 1978; Siegel, Bauman, Schaefer, Saunders, & Ingram, 1980; Svejda, Campos, & Emde, 1980).

Ironically, this particular body of research is best summarized by citing the criticisms that have been leveled against it. Critics point to the many methodological difficulties with this work, such as small sample size, nonrandom assignment to experimental and control groups, and artificial manipulation of data to establish differences between groups (Lamb, 1982; Morgan, 1981; Myers, 1984). Goldberg (1983) suggested that the experimental conditions of early and extended contact were confounded in many of the studies, and consequently, research questions regarding the effect of these conditions have not been adequately addressed. Nonreplication and a lack of similar findings across studies were also cited as problems with the research effort as a whole (Lamb, 1982; Lamb & Hwang, 1982; Smeriglio, 1981).

Most importantly, many authors have questioned the validity of the measures of the dependent variable employed in the studies. For example, the duration of breastfeeding, amount of time spent in the 'en face' position, and various forms of maternal touch have been used as indices of maternal attachment. Few of the investigators attempted in the reports of their research to conceptualize the underlying processes of attachment, or to provide rationale for the measurement of behaviors used as indices of maternal

attachment (Campbell & Taylor, 1979; Lamb, 1982; Morgan, 1981; Myers, 1984; Ross, 1980; Smeriglio, 1981; Trause, 1981). There was also little evidence in the reports that maternal attachment behaviors had been conceptually related to the feelings or attitudes of mothers. Finally, arguments have been raised as to whether a dynamic process such as attachment is reliably studied at a point in time, or whether it in fact could be measured by any one behavior or constellation of behaviors (Campbell & Taylor, 1979).

Rebuttals to these criticisms exist in the literature (Anisfeld, Curry, Hales, Kennell, Klaus, Lipper, O'Connor, Siegel, & Sosa, 1983; Kennell & Klaus, 1984). They do not, however, address the important questions raised by the lack of clear conceptualizations of the attachment process in the reports. Also, the need to establish a link between maternal feelings, attitudes, and behaviors was not considered in the rebuttals.

Mother-Preterm Infant Dyads

There are numerous anecdotal and clinical reports present in the literature in which writers speculate on various aspects of a mother's attachment to her preterm infant. Preterm birth is generally depicted as a crisis, and disruptions in attachments are assumed to occur due to such factors as mother-infant separation, interrupted pregnancy, and illness of the newborn (Beaton, 1984; Doherty, 1978; Kennell, 1978; Oppe, 1960; Parente, 1982; Prugh, 1953;

Sherman, 1982). Authors recommend, without the benefit of systematic investigation, various interventions intended to decrease parental anxieties and facilitate attachment (DuHamel, Lin, Skelton, & Hantke, 1974; Rivers, Rosenblatt, & Redshaw, 1982; Thornton, Berry, & Dal Santo, 1984).

Much of the empirical investigation of preterm birth appears to have been motivated by the belief that many of these infants are poorly parented. Investigators (Elmer & Gregg, 1967; Hunter, et al, 1978; Klein & Stern, 1971) claim that evidence exists to support an association between preterm birth and parental maltreatment of the infant. Minde (1980) however, questions a direct association, citing the important influence of factors such as socioeconomic status and chronic infant illness on the parent-infant relationship. He also points out that the lack of clear definitions of the terms child abuse and failure to thrive in these studies undermines the credibility of reported results.

In all, three possible theoretical explanations for the alleged disorders of parenting associated with preterm birth can be gleaned from the literature. First, investigators have examined parental response to the event of preterm birth, apparently hypothesizing that negative emotions impede the attachment process. Second, some investigators view contact between the mother and the newborn preterm infant as the crucial factor, speculating that the lack of intimate contact and/or geographical isolation between the

two in the period shortly after birth seriously disrupts attachment. Third, investigators have examined preterm birth and possible problems with relationships from the point of view that the different, somewhat unpredictable behavior of the preterm infant may adversely affect the attachment process. A summary of empirical investigations with a view to these theoretical approaches follows.

Response to the Event of Preterm Birth

Parents experience mostly negative emotions, at least initially, in response to preterm birth. Guilt, anxiety, shock, disappointment, and fear of infant death are almost always reported (Blackburn & Lowen, 1985; Harper, Sia, Sokal, & Sokal, 1976; Jeffcoate, Humprey, & Lloyd, 1979; Jinadu, Daramola, & Ikpatt, 1982; Lissenden & Ryan, 1982; Paludetto, Faggiano-Perfetto, Asprea, deCurtis, & Margara-Paludetto, 1981; Yu, Jamieson, & Astbury, 1981). Some parents experienced grief reactions similar to those occurring when a newborn has died, even though their preterm infant survived (Benfield, Leib, & Reuter, 1976).

Preterm birth has been classified as a crisis, and investigators have identified certain coping behaviors exhibited by parents during the experience which were associated with a mentally healthy outcome. For example, parents who consistently sought information and support and felt free to express their negative emotions had as good or better family relationships six weeks after the infant's

homecoming as they did before the birth (Caplan, 1960; Mason, 1963).

Maternal psychological tasks necessitated by the crisis of preterm birth were identified in other reports. Such psychological tasks include: anticipatory grief and subsequent withdrawl from attachments established during pregnancy, acknowledgement of the failure to deliver a term infant, and learning about the infant's special needs and growth patterns. Investigators claim that completion of these tasks is essential to the formation of a sound relationship between a mother and her preterm infant (Caplan, Mason, & Kaplan, 1965; Kaplan & Mason, 1960).

When considered as a whole, the results of research comparing the perceptions of mothers of fullterm infants with those of mothers of preterm infants provides ambiguous information. For example, in one study, no differences between preterm and fullterm groups were found on measures of maternal mood, acceptance, or concern toward the infant in the postpartum period (Smith, Schwartz, Mandell, Silberstein, Dalack, & Sacks, 1969). Jinadu et al (1982) also found no differences in maternal perceptions of the infant or in emotional reactions six months post delivery. Choi (1973), however, reported higher anxiety and depression among mothers of preterm infants. The findings of yet another group of investigators indicated that emotional disturbances, delayed bonding, and management problems at

home were more common to the preterm group (Jeffcoate et al, 1979).

Maternal Contact with the Preterm Infant

Investigators have examined interactions between mothers and preterm infants during maternal visits to the intensive care nursery. Findings indicated that mothers increased the amount of their interactions with the infant over time by more frequent smiling, vocalizing, touching, and looking 'en face'. Mothers also increased the length of their visits to the nursery over time (Minde, Trehub, Corter, Boukydis, Celhoffer, & Marton, 1978). Mothers who were highly interactive with their infants visited and telephoned more often, and stimulated their infants more at home, while the opposite was true of mothers who interacted less with their infants in the intensive care nursery (Minde et al, 1978). Parents of very ill preterm infants interacted less frequently with their infants than did parents of well preterms, and these low levels of interaction persisted at home (Minde, Whitelaw, Brown, & Fitzhardinge, 1983). In some studies, investigators used the number of parental visits and telephone calls to the intensive care nursery during the infant's hospitalization as a crude measure of maternal (parental) attachment (Daniels, Casaer, Buyse, & Eggermont, 1984; Fanaroff, Kennell, & Klaus, 1972; Marton, Minde, & Perrotta, 1981; Zeskind & Iacino, 1984).

Interestingly, the environment of the intensive care nursery may have a homogenizing effect on parent-infant interactions. With the exception of the first visit, mothers and fathers tended to exhibit similar patterns of interaction with their preterm, hospitalized newborns (Marton et al, 1981).

In a study designed to detect the effect of early separation on maternal attachment behaviors found no differences between two groups of hospitalized preterm infants and their mothers were found; one group had been allowed contact with their newborns, while the second group had little contact with their newborns until just before discharge from the nursery. A control group of mothers of fullterm infants smiled at their infants more often and held their infants closer to their bodies compared to the two preterm infant groups. Two mothers in the group separated from their preterm infants later relinquished custody of their infants, and five marriages in this group ended in divorce. One divorce occurred among the group of mothers who had contact with their preterm infants, while no divorces or relinquishments occurred among the mothers of the fullterm infants (Leifer, Leiderman, Barnett, & Williams, 1972).

Separation caused by hospitalization was associated with decreased maternal commitment to the preterm infant and with lower self-confidence (Leiderman, 1978), but these differences disappeared by one month after the infant's discharge from hospital.

The Role of the Preterm Infant in the Attachment Process

From the information available on attachment between mothers and their fullterm infants, one can assume that the corresponding process involving mothers and preterm infants also depends, to an extent, on interaction and mutual responsiveness.

Several investigators have documented the importance of the infant's state of arousal during effective interactions (Korner, 1972; Moss, 1967). Field (1977) found that preterm infants were less responsive than fullterm infants to some forms of stimulation, and had less capability to stay alert during stimulation. Magyary (1984) also suggested that the preterm infant has fewer alert periods compared to the fullterm infant, and exhibits disorganized, uncoordinated, and unpredictable responses to stimulation. The preterm infant may exhibit more "reflex" smiles than the fullterm infant during the early neonatal period (Goldberg & DiVitto, 1983), however, his cries may be perceived as more unpleasant and irritating (Frodi, Lamb, Leavitt, Donovan, Neff, & Sherry, 1978). Brown & Bakeman (1980) found that compared to fullterm infants, preterm infants were less active, exhibited weaker motor movements, smiled more, and cried less in the early neonatal period. If, as has been suggested, interaction is dependent on infant responsiveness (Goldberg, 1977), then it may follow that the attachment of mothers to preterm infants could be compromised due to the infant's limited ability to participate.

In conclusion, the literature provided incomplete, inconsistent information about relationships between mothers and their preterm infants. As with the literature on attachment between mothers and their fullterm infants, investigators conceptualizations of underlying processes were not made explicit in their reports, nor were rationales provided for the study of certain behaviors assumed to be associated with maternal attachment.

A major problem with the literature as a whole is that prematurity was inconsistently defined. Some researchers used the now obsolete definition based on birthweight, while most used the currently accepted definition based on gestational age (Klaus & Fanaroff, 1986). Most relevant to this research, no reports were found in the literature in which investigators attempted to examine maternal perceptions, experiences, or descriptions of their attachments to their newly born, hospitalized, preterm infants.

Maternal Role Acquisition During Pregnancy

Pregnancy has been described in the literature as a period during which the mother-to-be assesses, explores, reviews, and studies the nature of the interpersonal relationships in which she is involved. A woman's identity, both in relation to others and to her unborn child, is gradually reformulated during pregnancy, as a perception of herself as mother develops (Rubin, 1975).

During the first trimester, a pregnant woman "binds-in" or accepts the idea of the pregnancy and makes a personal assessment of the demands that motherhood will make on her (Rubin, 1975). At this time, the woman's own bodily signals, such as weight gain, enlarged breasts, and fatigue, are the only evidence of the reality of the pregnancy (Turrini, 1980).

In the second trimester, quickening, (fetal movement) provides the stimulus for the woman to bind-in to the child (Rubin, 1977). The pregnant woman now reflects on the essence of being given to and carefully considers her own ability to give to the unborn child (Rubin, 1975). The perception of fetal movement may be welcomed with a sense of relief that the pregnancy exists (Turrini, 1980), and may provoke maternal fantasies about the unborn child's gender and characteristics (Rubin,1970).

By the third trimester, the woman's concern for herself and her concern for her baby are no longer separate, as she strongly identifies with the infant's vulnerability and need for protection. Feelings of ambivalence surface: the mother wants to hold on to the baby, and at the same time wants to let go of the burdensome pregnancy (Rubin, 1970, 1975, 1977). Within Rubin's framework, there is a progressive investment of the maternal self in a bond to the child occurring during pregnancy. Other authors outline a similar progression of maternal identity development through pregnancy, as the woman gradually takes on aspects of her

role as mother (Bibring, 1959; Bibring, Dwyer, Huntington, & Valenstein, 1961; Pines, 1972; Osofsky & Osofsky, 1980).

Pregnancy has also been described as a normative crisis, which, while causing a period of acute disequilibrium for the pregnant woman, ultimately results in her maturation into a role as mother (Bibring, 1959). This process of maturation is stressful for the pregnant woman and involves a reorganization of her psychic equilibrium, a reorganization which may not be complete when birth occurs. However, the outcome of this crisis is thought to have an enormous effect on the early maternal-infant relationship (Bibring, 1959; Bibring et al, 1961).

Turrini (1980), on the other hand, stated that a pregnant woman's psychological preparation for motherhood is complete prior to the last six weeks of the pregnancy. This preparation involves acceptance of the reality of the child-to-be and the formation of an attachment to, but differentiation from, the unborn child.

Mercer (1985) suggested that a woman achieves competence in the maternal role through the integration of socially acceptable maternal behaviors into her established role set. According to Mercer, the formal stage of mothering begins at birth, hence the mother defines her role, at least partially, through her interactions with her infant. The mother evaluates her success in the role through her infant as well. That is, a thriving infant is associated with good mothering (Mercer, 1985).

In summary; most authors describe maternal role acquisition as a developmental process which has its beginnings during pregnancy. The mother-to-be's evaluation of her exisiting interpersonal relationships is important, as she incorporates a new identity for herself in relation to others and to her unborn child. The reality of the child-to-be is only gradually accepted by the pregnant woman, however, a strong attachment to the unborn infant exists by the end of the pregnancy (Rubin, 1975, 1977).

By today's standards, the gestational age of fetal extrauterine viability is past the stage at which most women experience quickening, at approximately 16 weeks gestation (Grant, 1979). Therefore, it seems that most women would have accepted the reality of the pregnancy before the delivery of a viable preterm infant could occur. However, no reports were found in the literature which outlined the effect of pregnancy interruption due to preterm birth on the process of maternal role development.

In conclusion, the literature provided incomplete information about relationships between mothers and their preterm infants. No reports were found in which investigators examined maternal experiences or descriptions of their attachments to their preterm infants. The effect that preterm birth, reduced mother-infant contact and limited infant social capabilities may have on the developing attachment relationship is unknown. In addition, the consequences of interrupted pregnancy for maternal role

acquisition, and its effect on the attachment relationship remains a mystery.

Chapter III

METHOD

The purpose of this research was to elicit and describe mother's experiences of attachment to their newly born, hospitalized preterm infants. This is a topic about which little is known, and the few related theories which exist only partially explicate the experience. Therefore, the grounded theory method (Glaser & Strauss, 1967) was employed in this study in order that basic theory relevant to this virtually unexplored area could be generated.

Grounded Theory

As a method of scientific inquiry, the goals of grounded theory include: the understanding through systematic investigation of the way in which a group of people define their reality and the accurate presentation of that perception of reality through the generation and writing of theory about it (Chenitz & Swanson, 1986). When employing this method the researcher follows a primarily inductive process, that is, moving from the examination of a specific social situation toward the development of a more inclusive general theory (Glaser & Strauss, 1967).

Several features distinguish grounded theory as a research method. For example, in grounded theory the aim is to discover and describe dominant processes in social phenomena. In grounded theory, conceptual frameworks are

generated from the data, not from previous studies. The collection of data and the sample selection are directed by the emerging theory, allowing the analyst to pursue leads in the data as they arise (Stern, 1980).

The simultaneous operation of the research processes of data collection, data analysis, and theory generation is the feature most characteristic of the grounded theory method. This feature, called the constant comparative method (Glaser & Strauss, 1967), is discussed in the next section.

Several assumptions about study informants are inherent in the acceptance of grounded theory as a viable research method. The first assumption is that humans organize and attribute meaning to their environment. The second is that attributed meaning, which has been created by the individual's experience, guides behavior. The final assumption is that individuals sharing a common circumstance ascribe shared meanings to their experience and act accordingly. The essence of the credibility of any grounded theory rests on a conclusion drawn from these assumptions, which holds that individuals in similar situations share the experience of a specific social problem which can be discovered, conceptualized, and described (Hutchinson, 1986). The processes of discovery, concept formation, and description are fundamental to the grounded theory method.

The Constant Comparative Method

In grounded theory, the constant comparative method of data collection and analysis is used. For the investigator, this means that during the simultaneous operation of the research processes of data collection, coding, and analysis, comparisons are continuously made. The constant comparative method has been described as a four stage process. It involves the comparison of all data incidents to each data category, the conceptual integration of the categories, the delimitation of a theory which describes the relationships between the categories, and the writing of the theory (Glaser & Strauss, 1967).

The process begins with the initial data collection. The analyst then codes each and every incident in his data into as many categories as possible. Incidents are coded to reflect the substance of the data, and categories are made up of coded data that seem to cluster logically (Stern, 1980). The basic tenet of the constant comparative method is that when an incident or piece of data is coded for a category, it is compared with all previous incidents coded in the same category. The comparison of all incidents in this manner stimulates the investigator's thinking about the properties of each category, in terms of its dimensions, conditions, and consequences, and relationships to other categories (Glaser & Strauss, 1967).

As the coding of data continues, the units of comparison naturally change from comparison of incident with

incident to the comparison of incidents with the theoretical properties of the category, and to the comparison between categories (Glaser & Strauss, 1967). Hence, the actual mechanics of constant comparison move the investigator to higher levels of abstraction of the data, and into the phase of concept development.

With the goal of a parsimonious theory in mind, the investigator decreases the original number of categories to a smaller set of categories which are at a higher level of abstraction and are more general. To this end, each category is compared with every other category to discover how they connect or are related (Stern, 1980). Categories are collapsed (reduced) and then combined to form broader categories and the relationships between them are suggested. Additional data are collected with the specific purpose of answering questions about the hypothesized relationships and to expand and saturate the general categories. These data either fit or do not fit the existing conceptualizations. The theory is modified if necessary, and concepts which are not supported by the data are dropped (Stern, 1980). The core category, which explains the relationships between all the categories and best identifies how a problem is processed, is conceptualized as the connections between categories become clear.

Relevant concepts which are extant in the literature are identified and compared with the theory as data at this point. This review of the literature serves to challenge and

clarify the theoretical notions of the investigator.

The investigator finally reaches an understanding of the social phenomenon under study, and makes a final conceptualization of how the problem is processed by the actors in the particular social scene. The analyst then attempts to present a systematic, substantive theory which accurately reflects the situation of interest.

The Sample

In grounded theory, the criteria for the study sample are determined so as to allow the investigator to examine the phenomenon of interest where it exists (Chenitz & Swanson, 1986). For this study, informants were selected based on their knowledge of the relevant social situation, and the following selection criteria were employed. In each case the nursing kardex was consulted to determine a potential subject's eligibility for the study prior to the investigator's first contact with her.

Selection Criteria

1) subjects had given birth to their first preterm infant between 25-34 weeks gestation no more than two weeks prior to study admission

2) the preterm infant was expected to remain in hospital for at least two to three weeks

3) subjects had delivered and kept at least one fullterm infant previously

4) subjects were married or involved in stable common-law relationships

5) subjects were willing to participate in three to

four interviews with the investigator and to have those interviews taped

6) subjects spoke English

Characteristics of Selected Informants

Demographic Data and Characteristics of Previous Pregnancies

The convenience sample for this study was comprised of a group of six women, chosen on the basis of their meeting the six selection criteria and their interest in participation in the study (Appendix A, Table A-1). Although two potential subjects, when approached, declined for personal reasons to become involved in the research, none of the study subjects, once admitted, withdrew.

In the study group, all mothers were living with the father of the preterm infant at the time the research took place. Five of the mothers were married to the father: four were married for the first time, one was married for the second time. The sixth mother was involved in a stable common-law relationship of six years duration.

All of the study mothers and fathers were Caucasian. One father was of Iranian descent and one father was of Danish descent, both were born in their respective mother countries. The ages of the study informants ranged from 26-36 years (mean=31.5).

There was some variation in the amount of formal education achieved among the members of the study group. Two subjects had reached grade 10, three had graduated from high school, and one had completed an undergraduate degree in

education. Only one mother was employed outside the home during pregnancy, as an elementary school teacher. Two of the mothers attended school during pregnancy, taking courses towards a university degree. All fathers were employed.

All study subjects were successful multiparas: two had previously delivered one fullterm infant, two had had two fullterm pregnancies, one had had three, and one subject had had seven previous fullterm pregnancies. Each of the prior pregnancies of the informants had ended in vaginal deliveries of healthy infants except one: one subject had had a caesarean delivery with her first child for failure to progress in labor. None of the mothers had ever personally experienced a miscarriage or preterm delivery, although one mother had had a therapeutic abortion for an unwanted pregnancy.

One participant had five children from her first marriage, and three (including the preterm) from her current marriage. Six (excluding preterm) of the eight children were living with her while the eldest was married and living on her own with her husband and two children. All other siblings of the preterm infants were from current marriages, were healthy, and were living in the homes of the study mothers. The ages of the study siblings ranged from 18 months to 20 years.

Characteristics of the Current Pregnancy and of the Preterm Delivery

Four of the pregnancies which produced the preterm infants were planned and two were not (Appendix A, Table A-2). One subject had her IUCD removed during the first trimester of pregnancy, and the second unplanned pregnancy resulted from unreliable contraception methods. Five of the pregnancies resulted in a single fetus, and one was for twins. Four of the mothers experienced bleeding during their pregnancies: two of undiagnosed origin, one due to placenta previa, and one due to uterine polyps. However, only one participant was hospitalized prior to preterm labor and delivery, this was for a period of ten weeks for diagnosed placenta previa and bleeding.

Preterm labor began spontaneously for five of the study mothers, while one caesarean delivery was performed before labor began for excessive vaginal bleeding. Four of the five deliveries were spontaneous vaginal, while one ended in a caesarean delivery, for twin malpresentation. One mother had a post caesarean tubal ligation and also had had an amniocentesis performed during her pregnancy for maternal age greater than 35 years.

Two of the study mothers delivered their infants in community-based hospitals. The first, the mother of twins, remained an in-patient at the community hospital for a period of five days after her caesarean delivery. One of the twins required care at a tertiary level nursery and was

transported soon after birth to the university-based Neonatal Intensive Care Unit (NICU). The second twin remained at the community hospital in a intermediate-level nursery.

The second mother who delivered at a community hospital was discharged in less than 24 hours. Her infant was also transported immediately after birth to the NICU. One informant was transported in an airplane from a northern location while in labor to the university-based hospital, where she delivered. In all, four study mothers delivered at the hospital where the NICU was located.

The four study mothers who delivered vaginally were able to see and touch their infants for a brief period of time immediately after birth. The two mothers who delivered by caesarean saw and touched their infants within 24 hours of the birth.

Five study mothers lived within one-half to one hours driving distance from the university hospital. Four of these mothers had easy access to transportation and were able to visit their infants in the NICU regularly. The fifth mother relied on relatives and friends for transportation. The sixth mother, who was transported from a northern location, chose to live in the university hospital hostel for the period of her infant's hospitalization.

Characteristics of the Preterm Infants

There were four males and three females (one set of female twins) in the study group (Appendix A, Table A-3). All except one of the infants were brought, as quickly as possible after birth, to the university-based NICU. The gestational age of the infants at birth was assessed on admission to the NICU using the Dubowitz scoring system (Dubowitz, Dubowitz, & Goldberg, 1970). By Dubowitz assessment, one infant was delivered at 26 weeks gestation, two at 30 weeks, one at 32 weeks, one at 33 weeks, and two (twin delivery) at 34 weeks (Mean=30.2 weeks gestation at delivery). All infants were appropriately grown for their gestational age, and birthweights ranged from 760 gm to 2620 gm.

There was variation in the neonatal course of the study infants. Six of the seven infants had respiratory difficulties at birth, all requiring assisted ventilation, at least initially. Four of the infants improved quickly and were weaned off the ventilator in less than one week. However, two of the infants were mechanically ventilated for prolonged periods of time, necessitating a slow weaning process, resulting in mild to moderate bronchopulmonary dysplasia. Six out of seven infants had bouts of apnea associated with bradycardia, most likely due to prematurity.

Two study infants required surgery in the neonatal period. Simple abdominal surgery was performed on one infant to close a draining mesenteric duct. Another infant required

surgery to create a ventriculovenous shunt for treatment of hydrocephalus due to intraventricular bleeding. One infant was diagnosed as having a patent ductus arteriosus, which was asymptomatic during hospitalization and left untreated.

All study infants received their mother's expressed breast milk when oral feedings were commenced, and all infants were initially gavage fed only. Among the group there were few feeding difficulties, as the infants generally tolerated their oral feedings once introduced, and made a slow transition to breast or bottle feeding once permitted. One infant did suffer from slow weight gain, and necrotizing enterocolitis was suspected, but not confirmed, in another infant.

The length of the hospitalization ranged from 23 to 109 days, dependent on the infant's condition and neonatal course. All infants, except the twins, remained in the NICU for the entire length of their hospitalization. As mentioned, one twin never required care at the tertiary level, and she remained at an intermediate-level nursery at a community hospital. For the parent's convenience, the second twin was transferred from the NICU to the community hospital as soon as it was possible. The twins then remained together until discharge, and went home on the same day.

When ready for discharge, four infants were totally breast-fed, two (the twins) were breast and bottle-fed mother's breast milk, and one was bottle-fed regular formula. At discharge, none of the infants required any

special treatments, external monitoring, medication administration, or supplemental oxygen. Three study mothers chose to "room-in" with their infants prior to discharge, providing 24 hour care for their child in the NICU setting for one or two days before taking him home. All study infants were discharged home to be cared for solely by their parents, with community-based professional follow-up.

The Setting

The data for this study were collected in two locations. Seven out of 17 interviews were conducted in one of two "rooming-in" rooms present in the NICU complex. These rooms are intended for the use of families whose infants are ready for discharge, allowing parents to spend a 24 hour period caring for their child in hospital before taking him home. The rooms, while actually part of the busy NICU, are separate enough to allow for a quiet, private environment for interaction between the informant and the investigator. The rooms were comfortable, spacious, and tastefully decorated to resemble a bedroom in a home. Siblings of the preterm infants accompanied their mothers to two of the hospital-based interviews.

Ten interviews were conducted in the homes of study subjects, where siblings were always present. The home interviews were usually conducted in the kitchen or the living room, at the preference of the informant. Except for final interviews which were always held in the subject's

home after the infant's discharge from hospital, the site for interviews was based on informant preference.

Interviews

In total, 17 interviews were conducted: four each with two informants, three each with two informants, two with one informant, and one with the final study informant. The number of interviews conducted with each mother was individualized based on the progress in data analysis and on the value and depth of the information obtained from the informant. That is, articulate, insightful informants were interviewed more often, as the information that they provided contributed more to the investigator's understanding of the situation at hand. Interviews were spaced approximately two weeks apart to allow for examination of processes over time.

The attendance of fathers at the interviews was neither discouraged or encouraged by the investigator. Interestingly, fathers did not attend any of the interviews. However, interviews were scheduled at the mother's convenience, and with one exception, this was during the day when fathers were at work.

Interviews were conducted in an informal manner. Guiding questions were utilized when necessary to stimulate the flow of information through relaxed conversation (Appendix C). However, the course or content of the interviews was not directed or controlled by the

investigator. Neutral or silent prompts were used to encourage informants to elaborate on their ideas or comments.

Notes recording personal thoughts and impressions were kept by the investigator during each interview. Interviews were tape-recorded with the subject's permission, and were later transcribed. After each interview, the investigator's notes were re-read while reviewing the tape, and further notes were made at this point, highlighting impressions, thoughts, and areas for clarification. Hence, later interviews with each informant became slightly more structured, as the investigator sought both clarification of previously obtained information and additional data. However, at each interview, attention was always focused on the informant's concerns of the time.

Ethical Considerations

Potential subjects were approached by the investigator after it was determined, through consultation with the NICU charge nurse and examination of the nursing kardex, that they met the first four selection criteria. The investigator then arranged to telephone or meet with interested persons at their convenience in order to discuss the research in detail and to provide time for questions and answers about the study. Initial interviews were arranged with those willing to participate in the research and informed consents were signed at the first interview (Appendix B).

Informants were advised of their right to withdraw from the study at any time without penalty. Subjects were also advised that should they elect to withdraw from the study, that it would be their option to decide whether information obtained to that point be destroyed or incorporated in the final study results. At the first interview and at all subsequent interviews, the opportunity for questions and clarification was provided the study informants. Interviews were always arranged at a time and place convenient for the informant. Informants were made aware of their right to discontinue an interview, for whatever reason, if they chose to do so. This right however, was never exercised.

At the study's inception, provisions were made for the referral of informants who requested additional assistance in dealing with their experiences to one of the two fulltime social workers practicing in the NICU. Referral of this sort was not requested by any of the study informants.

Subject anonymity was assured and protected by the assignment of code numbers to tapes and transcripts, and by the use of fictitious names in the study report. Tapes of the interviews were kept in a locked drawer in the investigator's home and were destroyed when the data analysis was complete.

A proposal for this research was subjected to an ethical review and was approved by the University of Alberta Faculty of Nursing Ethics Review Committee. Ethical review and approval was also obtained from the institution from

which the study sample was obtained.

Issues of Reliability and Validity

The products of grounded theory research have been dismissed by some as lacking in reliability and validity. However, such criticisms usually arise when the aims and methods of quantitative research are confused with the aims and therefore appropriately utilized methods of qualitative research (Glaser & Strauss, 1966).

The use of the grounded theory method in this research was appropriate in that the purpose of the study was to discover, conceptualize, and describe the mother's experience of attachment to her newly born, hospitalized, preterm infant. Emphasis should be placed on the reliability and validity of the theory and conceptualizations put forth by the investigator as an accurate representation of the social phenomenon under study.

Certain procedural criteria designed to promote and maximize the reliability and validity of the products of grounded theory research have been suggested. For example:

- the simultaneous collection, coding, and analysis of data (i.e. the use of the constant comparison method) to promote variation and verification in the data obtained
- the study of several comparative groups to allow for depth and variation in the data
- the placing of faith in the researcher's own knowledge which is based on her experience of firsthand data

collection and analysis

- the clear presentation of study findings including descriptive statements and data segments which depict the analytical framework
- the validation of the researcher's conceptualizations by informants from the social situation being investigated (Glaser & Strauss, 1966; Wilson, 1985)

In this study, the constant comparative method of data collection and analysis was employed. The basic social process of *forging a role* was identified, which best explained the way in which study informants processed the problem of attachment to their preterm infant. The analytic framework depicting the theoretical categories derived from the data and their interrelationships is outlined in the investigator's descriptions of the study results, and is illustrated with data segments.

The internal validity of the data obtained in this study was enhanced by the selection of informants based on their special knowledge of the topic area of interest. However, the investigation of comparative groups was not undertaken in this research effort due to time limitations and financial constraints.

In consultation with her thesis supervisor, the investigator was responsible for all data collection and analysis, and thus developed a unique understanding of the situation based on her firsthand experience with it. This understanding contributes to the validity and credibility of

the reported research findings.

The investigator's years of experience as a neonatal nurse seemed to endow her with automatic credibility in the eyes of study informants. That is, subjects stated that they felt free to talk and share with someone who was not shocked or confused by the events that were taking place. Comfortable relationships were easily established with all study informants, and the mothers shared their thoughts and feelings with the investigator in a remarkably open and frank manner. The use of an unstructured interview format for data collection presented minimal risk to the validity of the data obtained (Field & Morse, 1985). Knowledge of the tests and procedures the mothers described meant that the investigator did not have to interrupt the flow of the interview to clarify meaning with the informant. At times it was difficult for the investigator not to assume the role of teacher when the mothers asked questions. Generally, responses to questions were left to the end of the interview but on occasion it was necessary to answer them in order to maintain a reciprocal relationship with the informant. In all qualitative studies of this nature, the interview itself may influence the behavior of the informant but an attempt was made to minimize this by delaying responses which could be interpreted as teaching.

Validation of the theoretical thinking of the investigator was sought from individual informants on an ongoing basis. In addition, a single, lengthy interview was

conducted with one study informant when her infant was 88 days old and still hospitalized. Data obtained in that interview confirmed the investigator's conceptualizations derived from the progressive interviews with the other study subjects.

It is unlikely that the results of any grounded theory research could ever be exactly replicated, since no two researchers would analyze the same set of data in exactly the same way. However, according to Chenitz and Swanson (1986), grounded theory is ultimately tested for reliability through evidence of its use and applicability over time. The theory developed during this investigative effort represents a basic conceptualization of how the problem is processed by the participants in the social situation described. Hopefully, exploratory work such as this will provide a stimulus for further work in the area.

Chapter IV

STUDY FINDINGS AND DISCUSSION

The six women who participated in this research were "successful" multiparas, each having previously achieved a fullterm pregnancy and the birth of a healthy child. For the purposes of this study, it was assumed that each informant had developed through her prior experiences with pregnancy, childbirth, and mothering, an outlook, a mind-set, or an image of herself as a mother. It was also assumed that each of the informants had experienced the formation of attachment relationships with her previous children. For each study subject, the current pregnancy marked her first personal acquaintance with preterm birth and its consequences.

Prior to the birth of this child, knowledge of a personal, maternal role in relation to a hospitalized, newly born, preterm infant did not exist for informants. The drive to define a role in relation to her preterm infant arose from the mother's need to find a way to continue the attachment relationship she had begun with her infant during pregnancy. For the study mothers, definition of such a role was essential to the extension and further development of attachment in the postpartum period.

Learning from their experiences over time, study subjects built new identities as mothers of preterm infants. Each individual approached the task of role formation in a

unique way. However, commonalites in the experience were observed in the group, which allowed delineation of a process which describes the experience of the study mothers. The steps of forging a role, depicted in Figure 1.0, will first be briefly outlined and then described in greater detail in the following sections.

Overview of Forging a Role: A Basic Social Process

Study mothers experienced an abrupt termination of their physical attachment with their unborn child when the preterm birth occurred. The birth set the stage for the process of forging a maternal role in relation to the preterm infant to begin. All but one informant suddenly and unexpectedly found themselves in a situation that was unfamiliar and out of control. One informant had been hospitalized for ten weeks but even for her the time of the birth was not totally anticipated as a caesarean delivery was performed for a sudden hemorrhage. The process of forging a role began slowly as informants, in their initial reactions, tended to focus on their infant's physical appearance and on lifesaving neonatal technology. Fear and apprehension stalled the process of role formation and mothers concerned themselves with their infant's survival as the primary issue.

Forging a role continued on the condition of accepting. Once the infant's immediate survival was at least relatively certain, each subject, through accepting, learned to live

"with what life had dealt her" in terms of an unexpected and undesirable preterm delivery. At this point, mothers began to gather the emotional and intellectual energy necessary to proceed in the process of role discovery and definition, through acknowledgement and mobilization of new and existing sources of strength.

Once her infant had survived the early neonatal period, informants moved away from a narrow focus on the present time. Optimism, although reserved, seemed justified, and mothers became hopeful for both the present and future of their relationships with their preterm infants.

Study informants eventually became engaged in caretaking relationships with their hospitalized preterm infants. Initially, the mother's activities in this regard were inhibited by the infant's physical condition and by her own ignorance and fear. Forging a role depended on the subject's belief that her efforts at mothering were increasingly successful, fulfilling, and worthwhile. This belief was, to some extent, influenced by the mother's perception of her infant's positive response to her mothering.

During the period of her infant's hospitalization, each study mother came into frequent contact with the nursing and medical staff in the NICU. Out of necessity, relationships were established between informants and these individuals. Mothers described their interactions in these relationships

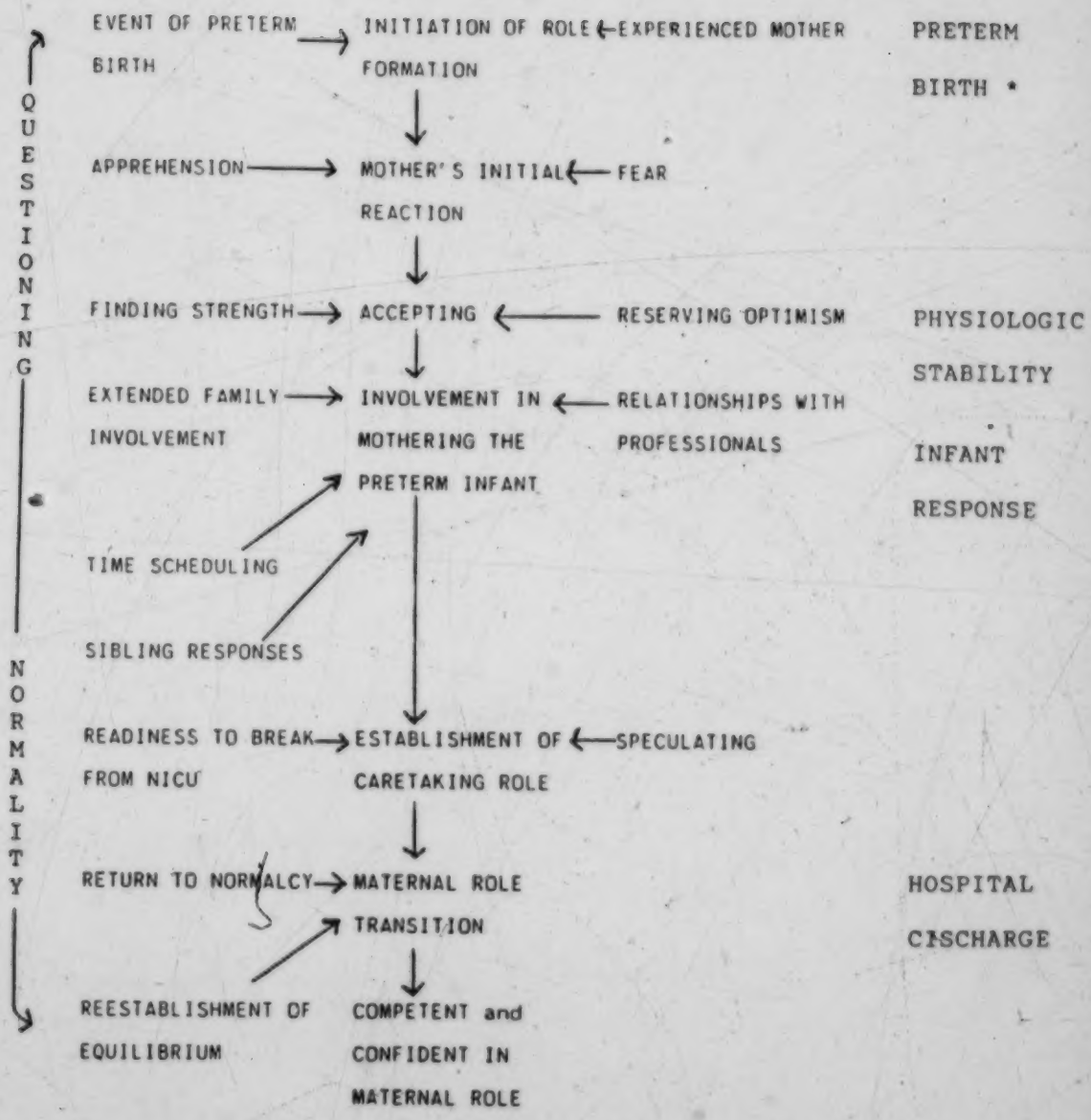

Figure 1.0 - The process of forging a role

* - events that determined a time frame for the process

which involved trusting professionals, working with nurses, and communications with the NICU staff. The subject's perceptions of the interactions that took place within these relationships varied, and the overall positive or negative atmosphere of the relationships affected the process of forging a role.

Without exception, each study informant had a child or children besides her preterm infant, as well as other family members, to whom she was responsible. Consequently, forging a role took place within the context of family involvement, time scheduling, and sibling responses.

Over time, mothers became familiar with indicators of progress in their infant's condition. Weight gain became a subject of great interest, as did the infant's physical movement through the NICU from the intensive care area to the convalescent care area. The infant's journey away from technological life supports was welcomed by informants as caretaking became more "normal" and less encumbered.

Mothers began to consider making a break from the NICU as the process of forging a role continued and the infant's physical condition improved. They began to speculate on the dynamics of personal and family relationships with the infant in the home, and to make plans to be prepared for the baby's discharge.

A return to normalcy and reestablishment of equilibrium in the home began with the infant's hospital discharge and occurred as a consequence of a transition in the maternal

role which had been developed to this point in relation to the hospitalized preterm infant. This transition in a sense involved a change from a "controlled" to a "controlling" role for subjects as mothers of their preterm infants. Sibling and extended family involvement with and reaction to the preterm infant influenced the role transition.

The need for study mothers to have formed an image of themselves as competent and knowledgeable in their role became especially evident during this transitional period. In the final study interviews, subjects described themselves as being "still very open to fear", fear which could easily be provoked by anxious responses to the preterm infant from health care professionals practicing in the community.

Throughout the process of forging a role, study mothers questioned their infant's physical and intellectual normalcy. The fear that her infant might not be or become a "normal" child was persistent for study mothers. All informants expressed a personal commitment to cope with any problem their infant might have. However, study mothers were concerned about how a disabled child would affect the family as a whole, and whether their preterm infant could or would have a "good life" if disability were to become a reality.

Iin the final interviews, subjects reflected on the events that had occurred since the preterm birth, and commented on how their lives and outlook on life had been irrevocably changed because of their experiences.

The process of forging a role as a mother of a preterm infant could not be assumed to have been completed when the interviews with study subjects were concluded. It was apparent however, that the role was defined and incorporated to the extent that each mother could function confidently and competently with her infant at home. Presumably, the process would continue as subjects adapted their role as mother of a preterm infant to the home, family, and the community setting.

Prebirth Experiences

Pregnancy Relationship

Most women experience some degree of relationship with their unborn child during pregnancy (Cranley, 1981; Leifer, 1980; Rubin, 1975; Stainton, 1985a, 1985b). Study informants were not different from other women in this respect. These mothers gave evidence of that prebirth relationship through their postbirth reflections on their communication with the fetus and their commitment to the pregnancy. Emily, the mother of twins born at 34 weeks gestation described the communication with her unborn that occurred during her pregnancy:

> So you got to the point where you just about knew them. I didn't know what they were, but you could sit and tap your belly and then rub, and as soon as you let go there would be a kick. You could talk and you could feel them just kind of roll.

Sue indicated the happiness that she and her husband shared, anticipating their baby:

> And my husband was so excited about having the baby. I mean, he was just so looking forward to this baby...we wanted this baby very much.

Advance knowledge that her infant was likely to be born preterm caused Anne to feel close to her unborn child throughout the pregnancy. This mother, who was hospitalized for 10 weeks before the birth of her child at 32-33 weeks gestation said:

> Well, like all the time I was in there (the hospital), eh, I knew she was going to be little you know, and premature and that, and it seemed to make her that much closer, I don't know why, just, maybe 'cause just her and I were there, going through all that together.

Knowing the gender of her child before the birth (through amniocentesis) made the pregnancy relationship special for Anne. She said:

> So I think that helps make you feel a little closer too, 'cause you know what, you know, you can name her...I used to sit there and talk to my tummy and talk to her...
>
> I made her a little quilt and a sweater and hat while I was waiting... and knowing, you know, it was a girl you could make it the right color and...and then we already had her named and that.

This same mother spoke of a commitment to her unborn child which helped her to endure her lengthy hospitalization:

> You know, before she was born the nurses asked me "well how do you keep going, how do you, you know, not get really upset and everything?", and I just used to tell them, "Well, every week I'm here is a week better for her", so it was the only way I could look at it, otherwise I think I would have gone crackers sitting in here.

Ending Pregnancy

For all of the study mothers except Anne, the labor and preterm birth of their infants was surrounded by surprise and confusion. Labor was denied in some cases by both mothers and health care professionals. Pam tried to ignore her labor when it began but was forced to reconsider:

> Scared, I didn't believe it, initially at home I thought this is false labor and kind of joked, well this can't be happening, but I always knew things were different so at first I ignored it and then I came to realize this is serious and this is very scary because it's not supposed to happen now.

Mary, who initially did not recognize the significance of her ruptured membranes at 30 weeks said:

> I don't think I realized right away what was going to happen. Because I wasn't having any contractions or anything when my water broke. They told me I might deliver, but I didn't think I was going to.

Later, when Mary did begin to have contractions, she believed she was in labor, but was told otherwise by hospital staff, and consequently questioned her own judgment.

> So, you know, it confused me. I've been in labor before and it felt the same to me, but I, you know, they couldn't see it. They thought I might be constipated or something and I just ended up spending time in the bathroom...the lady beside me heard me (crying) and they sent for a nurse, and I was fully dilated then. Like, I didn't know until right before.

Prior Knowledge

Before the birth of their own preterm infants, study mothers were basically ignorant of the subject. However, informants did have a vague awareness of possible problems or consequences associated with preterm birth. Pam:

> Just that it's not, they're not fully developed, so there would be, could be, problems, not would be, but could be.

Mary:

> No, no. I know about premature babies, but I don't, I knew that lungs were an issue with premature babies but I didn't know, I didn't have any idea of the seriousness of it.

With the exception of Anne, study mothers came to the event of preterm birth and the end of a (to that point) mostly normal pregnancy, abruptly and unexpectedly. Since each subject was an experienced multipara and had already achieved at least one fullterm pregnancy, the preterm birth may have been especially surprising. In contrast to an anxious primigravida who seeks to prove herself in this aspect of her femininity, study subjects could be assumed to have already incorporated a sense of power and success in the role of mother. However, their past experiences had little relevance to the preterm birth and the events that followed. At least initially, informants had no knowledge base which would help them understand or cope with the situation at hand.

Initial Reaction

The physical appearance of the infant after birth proved disturbing to some. Sue, whose infant weighed 760 gm at birth commented on her reaction to the size of the baby:

> I felt a little disheartened to see how small, you know, a baby of that size really is...You forget how small babies are anyway, and then to see one like that, it's really little...Nothing prepares you for

> seeing a baby that tiny...I mean my oldest boy was a small baby, but not one pound eleven, I mean, that's small.

Other mothers reacted differently. Mary said:

> They brought him to me so that I could see him first,(before transport) that was the only time I saw him clearly. He didn't look that bad to me, he looked good...even his size, he didn't look, you know, unviable or whatever.

Pam remembered feeling initially only relief that labor was over and a reluctance to touch her newborn son.

> Yeah, just briefly, (saw the baby) but I was too, just wasn't, I didn't see, I just wanted the pain to stop at that point.

She described her reaction to her son when she saw him again several hours later in the NICU:

> Scared, I didn't want to touch him, nothing, because I thought he might die, I wanted to stay away, you know...

As a group, the mothers seemed more affected by the appearance of the life supports connected to their infant than by the baby's physical appearance per se. Emily:

> When we first went to see her and she had an IV in her head, she had something in her arm, and her arm was all done up, and in her belly button, and in her foot, she had tubes down her throat and I thought, like, this is prematurity, this is too much on the brain...

Even a preparatory tour of the NICU before her infant's birth did not protect Anne from a negative reaction to the technology. She said:

> I knew she'd have it but it looked different on other babies than it did on my baby. Like, what really bothered me was the IV's and that...

In the period immediately following birth, mother's concerns tended to be present time oriented. Pam said she was "taking

it as it comes, I don't know so I don't expect too much". Sue explained that she was unable at that point to consider the future, as "survival was enough initially".

Accepting

As mentioned, the preterm birth of a child placed informants in a situation which was unfamiliar and "out of control". Feelings of guilt, frustration, and helplessness were unanimous among the study group. Dealing with negative feelings was essential to each mother's ability to "learn to live" with the situation at hand and to proceed in the process of forging a role. Informants came to terms with their negative feelings through accepting. Accepting as a part of the process of forging a role had several facets, and changed over time.

Accepting Failure to Achieve Term Pregnancy

Each informant had received a past affirmation of her ability to "do things right" through the successful completion of a term pregnancy. These mothers were not prepared to fail in their current pregnancy and except for Anne, all informants searched for a cause for the preterm birth. In each case, when their own doctors were unable to enlighten them, they questioned their own complicity in the event. Mary said:

> I didn't really think that I was doing anything to hurt the baby but I wondered after if I should have rested more. The doctor said that rest wouldn't have...(made a difference) I don't know. It's not something that I really dwell on a lot I don't think but I wouldn't say I'm comfortable with it yet.

Mary indicated a practical reason for her need to know about the cause of the preterm birth. She said:

> ...in my reading I search for little clues and, but I don't think it's so much to um, to, like to, what's the word I'm looking for,... like to blame myself for, but if it, if I ever got pregnant again I'd want to know what to avoid, like I just don't want to do that again you know.

For Mary, her husband's belief in her innocence was crucial. She gave birth while he was working out of town and remembered:

> ...when I was in the hospital, like, I can remember, you know, thinking that I was afraid to call him even, you know, I was afraid that he was gonna, I don't know, blame me like, I wouldn't have been surprised if he'd try to find something wrong that I'd done to cause this. But he's been completely, completely the opposite. ...That would have been hard to fight 'cause I you know (had) enough trouble with my own guilt and searching for what I did wrong without somebody else doing to me too.

Pam reflected on her behavior during her pregnancy, which ended at 30-32 weeks gestation. She managed to reassure herself through her reading that she had conducted herself so as not to have provoked preterm delivery.

> Well, all the books I've read have said, well, the mother wasn't eating properly and the labor came on because the child had a better chance of surviving outside the womb. But that wasn't the case with me.

Even Anne, who was the sole informant to know the cause of her preterm delivery (placenta previa), had difficulty accepting the birth. While she did not question the reasons for the event, she did struggle with the "fairness" of it.

> I used to feel, I don't know what you'd call it, unfair feeling, I guess, you know, it's not fair, why should this happen to her you know, this type of thing...all these other babies are born and you know, why does she have to have all this stuff

> but...it's hard to say...just a real shocking experience I guess you'd call it.

She predicted her future feelings in this regard:

> I think it will still be, you know, a little bit of, not really guilt, but you know, I don't know what you'd call it, but I'll feel, you know, kind of guilty maybe that she's behind other kids her age, that type of thing. You know, I think to myself, well, if she wouldn't have been like that, and this wouldn't have happened, then she would have been, you know, right up with the rest of the kids.

Other comments indicate that guilt was not the only issue at hand as mothers worked through accepting. A sense of sadness and regret permeated subject's comments to varying degrees. Even over time accepting was not characterized by a change in feelings about the birth from negative to positive. Rather, accepting meant facing reality and continuing on despite a multitude of negative feelings. Mary, whose son was born at 30 weeks gestation and suffered severe intracranial bleeding after birth resulting in hydrocephalus said:

> Well, I guess I have to (accept it). I do, I feel really badly about what's happened to him, because he just, you know, he would have been a normal baby, there was nothing wrong with him when he was born and now he's got who knows what you know, nobody really knows what or if he has to deal with...it's really disappointing and saddening in that way. I still, I don't think I, I'm never going to feel probably completely OK about it even if I knew exactly what it was.

Jacky became pregnant with an IUCD in place and at one point considered abortion. She predicted her ability to deal with her negative feelings about the birth based on a positive outcome for her infant.

> They're still there (the feelings)...but I think you

> learn to live with them. It's like somebody died and you learn to live with it. I keep thinking to myself, well, it's the IUD that did it, and in that case I should have gone with my husband's feelings that it wasn't natural and you know we shouldn't have gone ahead with it but...we're grateful now if he comes out of it, so why worry about that?

Knowing the Difference

The contrast between the preterm birth and the events that followed and previous birth and postpartum experiences influenced accepting. Study mothers were keenly aware of what they were "missing". Emily described her disappointment at not being able to celebrate in the "usual" way.

> ...because when you have a baby you want to spread the news and you want to...everybody in that ward wants to do the same thing.
>
> So like I had all these girls (in the hospital room) you know, and it was great because we all laughed and chuckled and like their visitors were, you know, they'd come in and see all the babies and not mine.
>
> There was just jelly belly. And this pain and an empty feeling and you knew that something had happened that like, there was nothing to show for it, and it was like, it was probably like a lot of women feel when they lose their baby at birth. There's nothing. And you want to cry but it would not do any good because they're not going to bring them (babies) to your room just because you're whining for them.

At first, subjects did not see many opportunities for mothering their infants in the NICU setting. This accentuated the differences with the preterm birth for study mothers. Mary said:

> Oh, it's really disappointing this way. I remember telling you before that you know, as far as the first week or so goes, I didn't notice a big difference because I actually got to be with this baby more than I got to be with my other ones 'cause I was, you know, uncomfortable and in pain, like the other times, and this time I wasn't so I could

> really focus on him, whereas before I had to, you know, I had a lot of time to focus on my own discomfort. And, but now, it's just like this is horrible, compared to having your own,... like being able to look after them. You know, like, nursing them and everything like, that's one of my most favorite things about children ever, is when they're little babies and nursing them and stuff. I just love that.

Emily was frustrated by her inability to do the usual things for her baby.

> Then you walk in there and it was like...you couldn't really hold her and you had to put through that thing (isolette) and then you couldn't feed her right away and pump her on the boob machine (breast pump). That was it. That was my baby. Bring in the machine. Pump her up. And it was just...different. It was really different.

Lost Intimacy

Intimacy with the newborn in the NICU setting was not possible, and was sadly missed by study mothers. Emily:

> I mean you can't touch them, but then at least you can sit and you can open them up (isolette) or you can talk to them 'cause you feel kind of ...like you want to say things to them, like I wanted to talk to them but you didn't really say what you wanted to say 'cause there was always somebody around and they're buzzing around your face and they're, especially at (the NICU) 'cause they couldn't leave the baby, because they have to be there to make sure everything is cool. You couldn't say what you wanted to say. Like they don't mind and you know they don't care but it's none of their business. You want to say it to your child and you want it to be on a one to one, not one and a neighbor.

Intimate experiences with previous children caused Mary to long for those same experiences with her preterm infant:

> You know, like I always crawled into bed in the morning and my husband would go to work early and I just, me and the baby in bed until like, eleven or twelve, and I really looked forward to that.
>
> ...but that's not to say it won't happen (the special time), just not the way we thought it

> was...like, he'll still be only four and a half, five pounds when he comes home so it's not like, he's still going to be a baby but you know, ... it's just hard to kind of get into sinc because you know before, with the other two kids they did grow up so fast that they weren't babies for very long. So, I kind of feel like the babyhood is slipping away. But when I stop and think, I realize, you know, of course it isn't... he's going to be a baby a lot longer than they were but...

Going Home Alone

Returning home from the hospital without the baby was difficult for study mothers. For Anne, leaving her baby became easier with time:

> Alot is just the idea. You know, you have a baby, you're supposed to take it home with you, you know, just not leave it laying there...that's my baby and I shouldn't have to leave her there...it's not so hard as when I was in the hospital and first left her, but still, you know, you hate to go and leave her.

For Mary, the initial parting was traumatic:

> And then when I got home...then I got home and everything was the same and I was going to have to go on doing the same things as before and it was hard (informant crying).

Chronic Sadness

Eventually, study mothers reached a point where their own guilt and disappointment receded from primary focus. However, a sense of loss and sadness remained a part of their day to day reality. Mary said:

> Sometimes it feels like I'm missing and something's slipping away but it isn't really I guess...it's more like I'm missing that part, you know, that it's something that I kind of... want, or long for, I don't know. Maybe, I'm trying not to use stupid words but it is almost kind of like an ache or something. I don't know. And you know, I still enjoy the things that I do with the other kids, you know, not all the time, that's true, but...you know, when I do manage to relax a little. I mean it's not just

> saying that my whole life is without meaning now, that's what I'm trying to say, because it isn't that bad...it's just that a part that, a part of it that doesn't feel whole. Right.

Jacky found solace in her children at home despite the less than perfect situation with her preterm infant:

> I don't know, no, I don't know. I wouldn't say it's, it's a gap 'cause like, it can't be any other way, like I can go home and hug my other two kids and we can think about him, that kind of makes up for it, I don't know. It's not that I feel empty or anything...No, (it's) definitely not (the ideal situation)...It is for him in that he needs the care, but it isn't for us.

Lost Control

Pam resented the lack of control she felt over her newborn's care.

> But again that's just me, until I have it in my arms or whatever I'm hoping to gain, I don't feel good until I have it, how can I 'till I really know I have it?...Like I need that, actually holding or having or...It still won't be the same 'till he's home, and it still will be a hassle, he won't be, how can, it seems to me how can it if he's not home he's not in my total care. There's still the intervention of other people...

Anne opted for making the best of the situation:

> Just that it's not all the time. Just make the best of the time you do have with her, I guess...Just wait for her to get big enough to come home.

Accepting as a step in forging a role depended on the mother's assimilation of her negative feelings related to the preterm delivery and hospitalization of her newborn. Informants needed to resolve for themselves the issue of their personal complicity in the preterm birth. Having no basis for comparison, or understanding of the situation based on experience, mothers felt frustrated and helpless.

However, despite extreme feelings of regret, informants experienced a growing personal awareness of their ability to cope with what had previously been unimaginable. This awareness provided a stimulus for forging a role to continue.

Finding Strength

A certain amount of emotional energy was required by the study mothers in order to deal with their infant's day to day situation and to continue in the process of forging a role. Informants turned to previously established sources of support during this time such as religious faith and family.

Religious Faith

All informants expressed their belief or faith in God, but described themselves as spiritual rather than religious. Their faith provided a source of strength. Mary said:

> Mostly, I'm drawing a lot on my faith, my religion and things, you know, at this point...Like yesterday was really hard for both of us, neither one of us were doing very well, and so we arranged to have another blessing for our baby and that helped me.

Realizing that she could not control her son's medical course, Sue turned to her faith in God:

> I simply said, "God, this is more than my shoulders can handle, this, this situation is too big for me to take responsibility for, I put it in your hands" and I sort of asked, I mean I'm not a religious person that goes to church all the time but I do have a tremendous faith in God.

Pam also relied on her faith for strength:

> And I get it (strength) from God, although I only, it's funny, I only asked him once for it, like I don't get, like when "D" was born I didn't pray, I

> couldn't pray...I just felt He was there, I guess God was there, you know...

Family Support

Mothers also drew strength from their marital relationship. All of the informants described their relationships with their husbands as positive.

Mary perceived her husband as alternately helpful and needful, and these characteristics facilitated her own mobilization of emotional strength. Her spouse was helpful in that he assisted with the care of the preterm's siblings and supported her decision to breastfeed her newborn.

> My husband has been able to come through in that area for some reason 'cause normally he's quite an out of patience sort of person and he's really seen the need with the other children and he's been able to fill that better than I have. He's spending extra time with them...(and) one thing that really helped was my husband's support, it was really important to him that I breastfeed so that helped a lot. If he was neg-, if he was against it too, I would have been hard pressed to carry it through, 'cause I can't have him upset all the time too.

He also acted as her comrade through the experience.

> It's not to say that there's not you know, other parts of my life are still fulfilling, like, you know, my husband and I are actually really pulling together well, like, you know a lot of times things like that can either, kind of you know pull you apart or pull you together, one or the other, and we're really, we're actually, we've actually become, like we're able to deal with the, deal with each others grief. Well not grief exactly, but you know, disappointment, and worry and stuff, together and not separately like, we understand each other.

Her desire to return that support and to be strong for him contributed to her resolve:

> ...actually the fact that we were able to understand each other and pull together is what helped, is what helps, because he needs to, you know, help me as

> much as he can, and so, you know, you don't fall apart when you know someone's relying on you...do you know what I mean?

A happy home provided a welcome respite for informants. Anne appreciated the distraction that her children at home provided:

> I'm just waiting 'till she grows and then get her home. But I think it's easier like, to come home to these two, little, little ones (siblings) here. 'Cause it gives you, you know, you're busy, you don't have time to sit and think about it all day long and worry about it...coming home to nobody would be a lot harder I think.

Jacky saw positive evidence of her ability to mother in her children at home.

> If I didn't have them I think I'd be totally zonked out...I would feel like a complete failure...in this situation the best thing I have is my other children to ah...for one thing I know they're normal and we did things right with them so to speak. You know, so I have the confidence that we have two other children and I can go home to them and create a good life for them.

Pam also drew strength from the positive reinforcement from past and present experiences with her two year old daughter.

> ...and it's a good thing I've had "A" at home and that I've established being a very good mother. I know that I am in comparison to my friends, just how I am, and my husband supports me and thinks I'm very good too, so I have that confidence...and thank goodness too, because if it was my first premi, I think I would have all kinds of terrible feelings and I would feel inadequate and I would not feel I would be a good mother, you see, but I know different so...

Establishment of a Routine

Study mothers found a semblance of order which bolstered their emotional strength once they had committed themselves to a routine for the way in which they would

manage their various responsibilities during the period of their newborn's hospitalization. Finding time for the newborn often meant taking time from siblings and other family members, leaving little time for themselves. For study informants, strength came from decision-making and commitment, no matter how taxing the routine.

Sue, whose family lived 180 miles from the university hospital, remained for more than 15 weeks close by her infant in the hospital hostel. For her, the choice was clear from the start:

> ...and I had this tremendous sense of, you know, the umbilical cord still connecting us-I didn't want to be away from him...I have felt right about what I am doing. I mean, I've heard a lot of mothers say to me, "gee you must really miss your kids and you must feel guilty about being away", and yes I do, I really miss my kids and I feel guilty about being here but it seems to have been the right thing to do...we worked out what my husband was going to do, what, how the children were going to be cared for, and everything else. It's just a matter of setting priorities and then working everything out. It's when you don't set priorities, and you don't know where you're going, and you don't know what your goal is, that everything is, all of your energy is pulled here and there...it was a matter of just uh, sort of channelling my energy to the one thing that I felt I could cope with and that was being here.

Jacky, in contrast, opted for a different plan that better suited her personality and her family's needs. However, she seemed to feel obligated to defend her choice:

> And I'm not so sure you know, if it's good for me to be there all the time. Like, I find that the other girls that come in here all the time, they're in the hospital, they live, die, and breathe their baby. Whereas I get out into the traffic, and my kids and my husband and you know, and get my mind on other things my ah,...I've got to believe that's best...for me, because I am a worrier.

For each mother, a routine provided structure around which to organize the rest of her life and responsibilities. Within the study group there was variation in what was perceived as an acceptable plan. The nature of the routine was determined by individual preferences, while the routine itself contributed to the mother's emotional reserves by providing a sense of stability and control.

A supportive spouse and happy home which provided positive opportunities for mothering were important to informants. Spiritual faith in a higher power also proved valuable during this period of crisis. These new-found or newly acknowledged sources of strength assisted mothers in proceeding with forging a role.

Mothering in the NICU

The process of forging a role continued as subjects began to search for ways to mother their hospitalized preterm infants. Initiation of touch was an important factor in establishing a foundation for informant's participation in caretaking.

Touch

Emily, who gave birth to twin girls, described her relief at finally being able to hold her critically ill daughter.

> It was like, if I could have held "D" I'd have felt better, and even I'd have felt better about seeing her. But I couldn't hold her and I think that really bugged me that I couldn't get my hands on her. It was just so long before I could and it was just...and I hadn't been able to see her and touch

> her or anything and once I got to touch her it was different.

Because of "D"'s physical condition, Emily was not able to respond to her in the same way that she did to "C". Emily described the difference in her feelings:

> The difference between them being, I felt like when I was with "C", especially when I got to hold her and stuff, like we went to see "D" when I started going to see her and coming back, it was such a relief to get back to "C" because I could pick her up, and I could hold her. And it was like she comforted me instead of me comforting her.

The urge to touch and hold was very strong but fears held study mothers back. Anne was disappointed by the limitations that technology placed on her contact with her infant.

> ...at first I was kind of scared to touch her, but, you know, like, you couldn't really do anything, you couldn't hold her or anything and that kind of hurt just standing to look at her, that, that was hard.

Jacky conveyed the message that she needed assistance in order to feel comfortable touching her baby:

> I mentioned (dirty diapers) to the nurse at the time and she goes, "Well, if you don't like it, you change it yourself, like, you can, you can uh, feel free to look after him yourself, you can manage just as well as we can, just go ahead", and that was right at the time, I think we were three weeks into it and I was like, almost scared to handle him and touch him and I wasn't comfortable with him, like I'd just sit there and look at him...

Sue described the relief she felt when she forced herself to overcome her fear of touch:

> ...when my baby was a pound and a half I could reach in and touch him but I was afraid to. There were times when I stood by that isolette and all the machinery was going and he was in, sort of, one of his down days, and I could remember standing there and thinking, I should touch him, I want to touch him, but I'm afraid to, what if, what if I make something happen, what if his saturations go, what

> if his, what if he has a bradycardia because of this, you know. All these kind of things, hesitating to touch him and yet wanting to so badly and then thinking, don't be stupid, get your hand in there and touch him, I mean literally having this conversation in my own mind, opening the thing up (isolette) and touching him and then standing there bawling like a baby. A sense of relief. Ahh, he's alright, I touched him, I'm alright, you know.

In contrast, holding and touching her daughter was hardly worth it at times for Emily.

> I didn't even want, I wanted to hold "D". But God, to get in there and she's got the belly ventilator on and tubes in her nose and throat, you got in her you got them in your arms and you just forget it, it's not worth it.

Mary was prepared to do without the gratification that holding provided, on the chance that it might harm her baby:

> ...but we kind of worry about, you know, putting added stress on the baby...then last night we didn't want to bother him. So we just, they asked us if we wanted to (hold him) but we said "No, just put him back"(in the isolette)...if it's gonna upset him or anything I don't want to do anything to aggravate the bleeding (intracranial)...I don't want to do anything at all that would hurt him and I can still hold him and touch him in the isolette.

Pam also controlled her desire for physical contact with her infant, setting priorities and anticipating the future:

> ...and I don't mind how long (I hold him) because I want him to be better, I don't want him to get sick so it doesn't matter if it's just a few minutes, just as long as he gets out (of the isolette). The main thing is that he has to come home right away, as soon as possible, whatever it takes.

Infant Response

During the period of postbirth acquaintance, study mothers searched for cues in their infant's behavior. In the early neonatal period, infants were perceived by study mothers to be basically inactive and unresponsive. Pam:

> No, he's very quiet, he just lays there, they don't do anything, just lay there.

Mary:

> My babies all slept a lot. He's a very sleepy baby.

Anne:

> (the baby is) not as active, and you know, she doesn't, isn't awake that much, you know, things like that... I don't think I've ever heard her cry, mmm, maybe once she did but just a little squeek, I don't think they'd call it crying, you know.

Concomitant with the their impression of the infant as unresponsive were mother's feelings of inadequacy regarding preterm newborn care. For study subjects, initially, mothering of their preterm infant had no operational definition. Sue described her frustration:

> There's very little that a mother in here can do for her baby...it's such a feeling of helplessness and frustration, of futility, ah, of uselessless-uselessness, you know, standing there and being of no earthly use to your own baby.

Jacky expressed similar feelings of helplessness:

> What can you do, you can sit and stare at him for only so long, like when he's sleeping...like he's getting my milk (through gavage feedings), that's the only thing that I can do for him now.

Anticipating the Future

During this time, study informants could only look forward to participating in the very basic mothering activity of feeding. However, anticipation of the event seemed to sustain them, and five of the six study subjects used a breast pump to maintain their milk supply for future breastfeeding as well as to provide expressed breast milk for gavage feedings. For informants, feeding meant

opportunities for holding and for physical closeness with the baby. Pam said:

> ...with the thought of starting to breastfeed at some point soon, um, then that will mean a lot more too 'cause then I get to hold him more...especially when he's out of his isolette, that will be very, very nice.

Jacky predicted a change with breastfeeding:

> Well, I mean, when I'll be able to hold him and sit in a rocking chair and nurse him, I'll have a hard time leaving...then I can really help him eh? Then I can be here and, and uh, give him something whereas if I'm just sitting beside the incubator there's not much I can do for him anyway.

Ann also anticipated a change in feelings:

> I think that'll help too, when you can go in there and you can feed her and that myself, it'll make us a little closer too.

Getting Involved

As time passed, informants gradually learned to become more involved in the day to day physical caretaking of their infant. Jacky:

> Now I participate a bit more in his care. I was encouraged to do so, I was scared up until then...so now when he poops and stuff I clean it up ...and I put his socks on, and that's about it.

Mary described a broader scope in her involvement:

> ...I try to make him more comfortable and like I can move him around a little bit and put his hat on...I took some little socks down for him to wear. I do as much as I can, you know, I just can't really do that much, but the few little things that I can do...I took some little toy down there and like we talk to him about it and I sing to him, and actually all my family visits him a lot, there's always at least, besides myself and my husband, there's always at least three or four people that visit him just about every day.

Despite their increasing involvement, experiences with

caretaking were less than rewarding for informants at times. Technology was inhibiting,

> And it was awkward because I had to do it through the isolette. And like I just wasn't used to that.

fears persisted,

> I don't like bathing him that much, but I really like you know, changing his diaper and doing the other stuff. Bathing him does make me kind of nervous. I don't really like pulling him apart like that.

and mothers compared themselves unfavorably to the NICU nursing staff.

> I think I make him cry sometimes, not used to, well, he's not used to me I guess you know, nurses know exactly how to move him.

As the study infants grew stronger and were physically able to be more active, their responsiveness to mother's care increased. Jacky's comments underscore the importance of that responsiveness as a reinforcer and facilitator in the developing mother-infant relationship:

> Like yesterday was the first time I really like, I looked into his eyes and he made me figure, well, I have a baby here. No it's the truth, like I looked at him and he looked back at me and that's the first time I've experienced that with him, whereas the others, it was very early. But I find too, that I feel differently about the baby that...at first he wasn't a baby, he was just, I don't know what he was. I didn't feel for him you know. But now when I go in, like, I hold him in my hand, and he looks at me and opens his eyes so, like I'm, he's starting to be my son now. I look at him and I wonder what kind of baby he's going to be. Like, I look, I search for his character but you, but I don't know yet. But I think it's just the beginning of a relationship when that happens, when you start to uh, look at each other and hold him.

Breastfeeding

Breastfeeding seemed to provide the most satisfaction in terms of mothering in the NICU. As an aspect of mothering, it helped to minimize informant's frustration with the situation in general. Mary:

> ...Well, I've found that nursing helps because I get to have him out a lot more so I hold him, talk to him and stuff. The rest of the time I just want to get out.

In a sense breastfeeding provided a key to the future. Jacky:

> That's going to be the, well that's going to be the pivot point where, you know, as soon as he learns to nurse, he can come home. But he's more or less my baby now, like I can come in and demand nurse him you know, whenever he needs it. Or that's the point that we're gonna, that we're leading to, like I guess it only starts once a day, or whatever.

Pam:

> ...I did not feel I was doing anything for him until I was nursing him...and then once that happened I wanted more of him and once that happened I started getting a little more impatient because you know, no you can't do too much because it's still, like I said, it's still they have their schedules and...

Mothers viewed feeding as the most satisfying mothering activity in the NICU because of its association with holding and physical closeness to the baby. Unfortunately, it was also the last mothering activity in which study subjects became involved since the preterm infants were gavage fed for extended periods of time, and mothers were not permitted to gavage feed. However, the pumping of breast milk provided an important link to this aspect of mothering, as did the anticipation of future breastfeeding.

Mother as Informant

One additional facet of mothering in the NICU was described by two of the study subjects. These informants believed that they were especially knowledgeable about their preterm infant by virtue of their consistent daily contact with him. They described themselves as being privy to special information about their infant's "patterns". Mary said:

> ... because the nurses do change so much and I am here all the time, I have been able to pass on a lot of information, like a lot more than you might think. I don't think that I've been totally useless. I mean even to the nurses, I've been able to see, you know, patterns and things that they might not pick up on.

Sue:

> ...for me there is no question, you know, this is my baby, I've watched this baby every day, except those twelve days, I know him better that anybody, I know his patterns, I know his behaviors, I know what makes him happy, what makes him uncomfortable...I try not to be pushy, I try to say things in such a way that, that it's conversational...introducing information into the conversation without being overly forceful about it. And sometimes, I don't know, I feel phony doing that, do you know what I mean? Like it's not something I should have to beat around the bush about. I should be able to say, "These are the things that my child likes and dislikes, and I have noticed these patterns in his behavior", because I have a tremendous amount of information about this baby that you'd have to go back and read a file this thick to begin to know him like I do...I'm not saying that every mother has the capability to stand and make observations, but if you have a mother who can observe these things, she should be part of the care, I mean, a primary part of the care of that baby, not just peripheral, not just an interested spectator, a bystander...

These two mothers were aware of their ability to observe, interpret, and store information about their infant's cues and responses to various interventions. Sue's comments

convey her perception of the uniqueness of this aspect of mothering. The reaction of the NICU staff to this mothering activity is not clear, but it seemed to reinforce for these two subjects their image of themselves as competent and knowledgeable in relation to their preterm infant, which in turn furthered the process of forging a role.

Bonding

The terms bonding and attachment have been used in the professional and lay literature since the 1960's. Study mothers were familiar with the lay interpretation of the concept and compared the developing bond with their preterm infant to that established with their previous children.

Several subjects described themselves as avoiding an intial bond with their preterm infant, due to the fear of his death. Emily put off going to see her daughter at first:

> ...like I didn't really want to see her on that when she first left (was transported to NICU) after all that stuff I'd seen her hooked up to before she left, I thought, I can't see her that way, she's just going to be a helpless little thing that I'm going to lose and I'd rather not get attached before I lose her...so then it took me that long to be able to see her because I didn't want to when I thought I was going to lose her.

Jacky described avoiding emotional commitment by concentrating on her infant's medical progress.

> ...it's almost like you're scared to get close to him because you might lose him...(initially) I was just following his medical progress.

A vote of non-confidence by a caseroom nurse reinforced Pam's fear. She described her first contact with her infant

in the NICU:

> I have to tell you that when "D" was born the delivery nurse said like, "He's alive", but she was sort of surprised, and then we were talking about who would do a vasectomy, what kind of doctor and she says, "well, I'd hold off on that", you know, so she's not so darned positive either.
>
> ...so when I saw "V" (NICU nurse) I was afraid to touch him and get attached and she said, "oh don't say that", but I should have told her, "well, this is what the nurse had said", so no wonder I'm going to say alright, it, like, she was surprised he was alive too.

Mary, on the other hand, remembered immediately feeling close to her baby.

> I bonded very easily with my kids, like when you hear about the people that have problems with postpartum blues, you know, that breastfeeding doesn't always start off right, and you don't always bond right away, like they try to warn you about stuff like that. But I always felt close to the baby right away... all my babies and this baby too.

She equated the emotional trauma she was experiencing with her preterm infant to that associated with her first child:

> I can't really tell how different it is, like the bonding, I think this baby and my first baby are more similiar than my second baby, maybe because the first baby was my first and because this one has had so much adversity to deal with. Not to say that I don't love my second baby. It was more routine I guess.

Jacky pointed out the effect that the lack of opportunities for parenting had on the nature of her bond to her preterm infant:

> ...we haven't been parents to him yet,...like our other children. Like, we haven't guided him through his first two months, the hospital has, like we've barely got to touch him the first two months... I think it's a different sort of love...I think in retrospect, I think we'll ...love him more, or he'll always be more special, or special in his way because of what he's gone through...maybe we'll

> overprotect him or you know, whatever. I think we'll more than make up for, we'll try to make up for the first three months of his life when he gets home.

She rationalized some aspects of the situation:

> ...if you think of it, he's supposed, he's still supposed to be inside of me, right, he just needs the incubator, he doesn't need me yet. In April he's supposed to come home, so he's going to get what he needs at the same time the others did. That's kind of a platonic way to look at it but it's the truth. If you think of it, maybe he doesn't need those cuddles and that bonding right now, because he's, he was only six months old when he was born.

Informants perceptions of their bond to their infant were influenced by their faith in its reciprocal nature. Not all subjects believed that their infants recognized and were in turn bonded to them as mother. Anne:

> Not really, no I don't think she distinguishes that much. I don't know. It's hard, you know, to know 'cause like they say, when you go in there that they know, she knows our voices and that, we sit and hold her and she opens her eyes and that, but whether she really, you know, there's so many people there she's going to take her awhile to associate who Mommy and Daddy are and...

Jacky:

> ...like how can "H" when he, he sits with me, and I uh, talk to him or cuddle him in here every day for a half an hour, or whatever, can he distinguish between me and a nurse that does the same thing three or four other times during the day? He can't. It would be nice if he could, but you know, like there's warm and loving nurses in there that coo to him and everything else, like, and they're very gentle with him too...unless they (infants) have a keen sense of...a smell or a feeling that they can distinguish a mother from a nurse, I don't know. But as this point I don't think he can, I honestly don't believe it.

Mothers who were convinced that their infants knew them relied on the infant's behavioral cues for that belief, interpreting smiling and settling as positive responses to

mother. Pam:

> ...Yes, he smiles (when mother is there)...especially with his Dad, he smiles a lot.

Sue:

> ...his response to my voice...and my touch. Quite often when he's fussing and really aggravated by some procedure, maybe gavage feeding or something of that nature I will put my hands in (the isolette) and, and he settles down within seconds... so he knows, he definitely knows me.

Mary:

> I don't know if he knows for sure or not. I guess I like to think that he does, not because it will make me feel better but because I want him to get as much comfort as he can because of what he has to deal with. He seems really comfortable when we're there.

After looking back at photographs taken shortly after her son's birth, Jacky became convinced that an unconscious bond to him had always existed.

> ...we take pictures of him every two weeks...and when he was born and even at two weeks, we thought he looked like a perfectly normal hap...you know, healthy baby, and now when I look back at those pictures, I can understand how my brother couldn't look at him...then (after birth) I thought "Geez, he looks in great shape", like that's gotta be that parental thing that you won't realize that, that's a strange feeling. 'Cause I remember we, my husband commented to me when we saw him first, "well, geez, he doesn't look bad considering what he's been through, he looks good", you know we even said to ourselves, "he looks just like (sibling)...he's in better shape than (sibling) 'cause (sibling) was all bumped and bruised and he had bruises all over his face... we said that he looked better than him but now when we look back at those pictures we're just overwhelmed...like his skin's just hanging there, and he's lying there, you know, like that.

Mary described a similiar experience:

> I think I told you we got some photographs of him when he was sick...I got them back...it just made us both feel sick. You know, so I really got used to the way he looked and I didn't realize how bad he

> looked until I got those pictures back and compared him now. So, we couldn't look back at them but...I think when I look back, what I remember in my mind, like I always thought he looked, well, because he was my baby I never really saw, I must not have seen him the way he was, you know, he must have always, like he always looked fairly good to me but my expectations for him were higher than, like, the staff,' and I didn't realize until after, but he didn't look that unusual or abnormal to me. Like he was small and that, but I think I remember telling you...the bigger babies that would come in, they looked almost like something was wrong with them, like, they were diabetic or something.

Jacky expressed her concern that such "blind parental love" might hinder objectivity towards her son:

> That's strange isn't it. That's why I would think that we could...easily go through fine for the next five, six, seven years and not realize that he has a problem, just because of our love for him and our...need to want him to be normal.

Over the course of the research, study mothers expressed varying perceptions of their bond or attachment relationship with their preterm newborn. However, through their behavior, all mothers consistently showed culturally acceptable signs of a commitment to their preterm infant. For example, informants named their infants. All study mothers visited their infants at least daily, if possible. Informants sought and received a daily update on their infant's condition and progess. In addition, study mothers repeatedly made comments that indicated a feeling of ownership for their infant. Referring to the infant as "my baby" and as a member of the existing family were examples of this.

Five of the six mothers pumped their breast milk for gavage feedings, and over time became as involved as possible in the physical care of the infant. Study mothers

also attempted to ease the acceptance of the preterm infant into the family by bringing siblings and extended family to visit the baby while in hospital.

It may be that these behavioral expressions of commitment and caring were, to a certain extent, controlled by societal, cultural, and family expectations. However, the work of Rubin (1984) supports the importance of this sort of "claiming" behavior to the overall process of maternal role formation. The emotional, personal "letting go" involved in a conscious bond or attachment on the other hand, may have been withheld by some of the subjects until they felt ready. It is not clear whether mothers who described themselves as intially avoiding a bond changed because they felt the risk involved in that attachment had lessened, or because they eventually felt ready to take the risk, regardless. All study mothers eventually spoke of a bond, and their awareness of it seemed to provide a stimulus for forging a role to continue.

Becoming Hopeful

Forging a role was contingent on informants becoming hopeful. This aspect of the process occurred on a continuum between hope and despair. Hope depended on the mother's awareness of signs of her infant's progress, while despair was provoked and deepened for informants when setbacks and deterioration in the infant's condition occurred. Hope was more readily attained and held by mothers whose infants had

a placid neonatal course. Conversely, despair was almost overwhelming for informants whose infant suffered setbacks. Mary, whose son was critically ill, said:

> ...both my husband and my ... feelings have pretty well fluctuated with how, like, with the baby's daily condition...it's funny but like, even the tiniest little setback will just practically throw us into despair. You know, they just, up and down, up and down...we really want, actually we're not really taking it that well now.

Repeated setbacks in her son's progress made Mary want to escape the NICU:

> I don't know, like I just got down so bad, really, when he started to get sick again that I didn't even want to be there. And usually I'm quite the opposite, like, I've always wanted to be with him as much as I could.

As the despair deepened, relatively innocuous signs of possible problems were blown out of proportion, moving Mary further away from hope.

> And like, I'm getting less and less stable now, like I was telling you, you know, his temperature went down a little bit the other day and I was just totally hysterical, and today, I went, I just went in that milk room and I mean, I just sobbed my heart out.

Signs of progress, on the other hand, moved mothers towards hope for the future. Physical movement through the NICU from the intensive to the convalescent care area was an important, tangible sign of progress for informants. Pam:

> ...he's doing ok and that he's gaining and he's moved to the fourth row (convalescent area) so that's very positive.

Anne:

> I think it's 'cause I know she's getting better 'cause she's advancing, every time I go see her she's moved up a step, and now she's you know, in

that little room (convalescent teaching unit) so...

Jacky:

> I got into the other, row four, is it, just when they were cleaning up and getting ready to push, so I got to push him (into the convalescent teaching unit), I felt pretty proud.

Pam:

> Once they're in the CTU (convalescent teaching unit) it's more like a nursery, and it's everyone's happy 'cause now they're OK, there's nothing wrong...that was so good because everyone can laugh, like the nurses are laughing there, you know, not in the second row where it's so serious.

Infant weight gain and the removal of technology were other crucial signs of progress. Pam's comments indicate the way in which her feelings were tied to her perception of her son's well-being.

> We're very happy 'cause, I'm very happy, he gained 60 grams last night so... 1730 now and I'm really happy about that. He lost 10 the other night and that really was a downer...sometimes I question the scales so sometimes they're just not, one night he'll do really well and the next time not, so...and then he gained 60 last night and that made up for it...when he loses I'm blue and then when he gains I'm very happy.
>
> When there's a concern then they'll ...he'll get another IV (intravenous) in his head, they'll change his procedure or whatever, they'll change something, and they're only changing it for the better. They're taking away, not adding, so that's where I'm getting it (hope) from.

Despite progress, maternal optimism remained guarded as fear of setbacks persisted. Jacky said:

> I'm not confident in that I'm a pretty guarded person, but everyone else seems to be so very confident, and they told me yesterday that he'd be home in six or seven weeks and that he was going to be fine, so, I really have no reason to be, apprehensive, but, it's still at the back of my mind, but I feel pretty good about it. I'm still

> just as concerned because he is in the intensive care unit, and things could turn, you know. He could have a setback and things will be back to square one tommorrow.

To Anne, the fear of setbacks did not seem logical, but persisted nevertheless.

> And there's still that little bit of fear that something could still go wrong, but, she's doing really good, so I don't have to worry about it really. You know, deep down, it's still there.

Pam depicted her transition to guarded optimism as being dependent on her son's continuing progress.

> I don't want to be too hopeful because I might come in and it isn't. That was initially the first few days, don't be so lighthearted 'cause you could come in and it could be bad. But generally now our feelings are quite on an even keel so...and now we're very hopeful, now we think he's very normal and he's going to be normal when he comes home, but still we like to hear it. We still like to hear, "oh yes he's doing..." you know, we still like to know he's doing well.

Hope grew for study mothers as signs of progress came more frequently and were more reliable. A guarded optimism was always maintained however, perhaps as a protection against future disappointments. However, this reservation of total optimism did not seem to affect the process of forging a role. As long as there were some realistic, tangible reasons for hope, mothers had sufficient incentive to continue in the process.

Relationships in the NICU

With the preterm birth of her child and his admission to the NICU, study mothers were introduced to an unknown environment and culture. Informant's descriptions of their

initial encounters with the NICU evoke a mental image of "strangers in a strange place". To the uninitiated, this environment is one characterized by high technology and an aura of crisis, while a specialized knowledge, established hierarchies, unfamiliar modes of functioning, and rules and regulations typify its culture. Despite its strangeness and potential unattractiveness, these mothers were drawn into the NICU and formed relationships with the professionals who practiced there.

Working with Nurses

Of the staff practicing in the NICU, nurses spent the most time dealing directly with the newborn patients and their parents. NICU nurses exercised some influence over each infant's plan for care, and consequently were in a position to encourage the mother's involvement in that care and thus facilitate the process of role formation. Informants described both negative and positive aspects of their relationships with the nurses working in the NICU, and these interactions affected the process of forging a role.

Informants were able to identify specific characteristics of "good" nurses. The nurse's ability to maintain what was perceived as an open, warm attitude towards mothers was important. Jacky:

> ...at first it's a shock to come in there,...if you get a really nice nurse, and we had many, they'll explain to you the whole situation and you'll go home feeling so good.

Pam:

> Some people I just don't like in there, not many,

but most of them are very good, just my type of person so...and what would help being that is that they can talk, like "V" (NICU nurse) would say exactly what it is and carry...take care of our feelings, like she took care of them, and was very good I think...she carried me through a lot of things by just talking without even asking me my concerns.

Anne:

...they were all really friendly and really willing to answer my questions, and I got to hold her (infant) before I left (for home) and that, they were really good that way.

Nurses who recognized mothers and conveyed a sense of welcome were appreciated. Anne:

...when you go in there they recognize you, they don't treat you like an outsider, they just, you know, "come on, do you want to play with her, do you want to hold her, do you want to bathe her", so that's really good that way, you know. They don't treat you like an outsider or like you're left out.

Nurses who made an effort to involve mothers with their infants were perceived as supportive and helpful. Pam:

..."V" encouraged us to talk and encouraged us to stroke him right away, and at first to talk was very hard, because, gee, talking through an isolette...she (nurse) was very, very good. And I was saying, "I'm scared, I don't want to touch him" and she was saying "Don't say that", just very nicely, not forcing or...very calm, quiet. She was a good first nurse to have on I think. Very good.

Mary:

Sometimes I'm disappointed when I go in and see ...it's somebody that I don't really...there have been a few that are very detached and, some that don't even really...want to talk to you about much, and that kind of disturbs me. Like I like the nurses that feel like they can talk to me and, that I feel are being really open and honest, and that notice, you know, little subtleties and share them with me and, I really, actually it's very important to me. And some of them don't, you know, share a lot. I'd say that most of them do, but I've noticed that the more that the nurses have "J", the more open they

become. I think you know, that they get to know the baby, I guess that makes it a little easier for them to share things and maybe they just don't have a lot to share at first.

Informants appreciated nurses who were mother-like in their care of the baby. Anne:

> ...you can tell they care 'cause they play with her, you go in there once in a while and they'll be tickling her or something, you know, and that makes you feel good. It's not like she was laying there abandoned type of thing. They call her by name and everything, you know so it's a lot more personal, it's not just like she was a number or something in there.

Mary:

> I think I told you already that, what the nurses that, like, you can tell the difference that (they) tried to make, that weren't, you know, (just) caring for the baby, that tried to make him really comfortable and stuff too, and a lot of them will, will talk to him, and you know, he needs that, some of that stimulation so that he's not just there being worked on all the time you know. When they are a little bit attached I really like that, I think that he's going to get better care then.

Some nurses were perceived as care-giving experts who perhaps worked at not getting involved, with mother or baby.

Emily:

> ...well, it's not that you guys aren't tender, it's just that you guys move a lot quicker that I do or anyone else that I know of, like in my family. Like we're all more cautious and more gentle. You guys know what you're doing so you kind of like, it's like I watch them and it's like they're flipping pancakes sometimes. You're so quick.

Mary:

> ...all the nurses are so different too, like, actually a lot of them do try and make him quite comfortable, but they do, it's more a kind of a, a lot of times it can be a kind of clinical touching, and...that's not true for all of them, a lot do spend the time just touching him and stuff too but, they probably work, I would think that they work at

not you know, not getting too involved.

Informants described themselves as able to accept NICU nurses as individuals with needs and personalities of their own. However, the general perception among the study group was that not every nurse "had what it takes" to be supportive or empathetic in their relationships with the mothers. Jacky:

> I think that the ones that are successful at it, like, from the minute you get in there they're talking to you, they explain what they're doing and "would I like to try it" or "here, I'll show you how" and, some of them don't even come over and say "HI" or anything, then when they come over to change a diaper they just whip in there and whip out of there again, like...they don't wanna hang around,...they could take time out to explain to you or whatever, and, and some of them just don't have the personality for it...some of them don't realize what you're going through. I don't know whether they do or not, but what they say gives you an indication that they have no idea what you're going through. But they're there to care for the child, they're not there to, to analyze us, like how can they deal with the stress of working in there and then have to deal with us too? That's a full-tilt job. That takes a special personality to work in there and obviously a lot, some of them don't have it.

Study mothers sometimes felt intimidated by a dogmatic approach on the part of nurses, resulting in frustrating interchanges. Jacky:

> ...they'd come across as a complete authority instead of a person that wanted to...you know what I mean? You know how you're intimidated by that...it's like talking to a doctor right, like he's, you don't always feel comfortable with a doctor when you go in and see him so you're scared to bring some things out right? It's the same with some nurses, like you're intimidated so you don't open up to them, you have to have a special skill not to be intimidating so a parent will open up to you...like if I won't open up to them and, or a parent is scared to open up to them and express their concerns then it doesn't do any good if they're talking to us anyway.

Coping with rules and regulations proved difficult for study subjects, especially given their perception that those rules could vary depending on the nurse. Rules enforced without input from the mother lessened her feeling of ownership for the baby and caused friction in the nurse-mother relationship. Pam:

> I know he's not mine, I have to contend with the nurses and they have their rules and their routines.

Emily clearly resented the situation at times:

> When you're in the hospital I feel like you should do it their way so they're happy. It's their nursery, it's their place, their responsibility. I guess they should do what they want but it's not their baby. 'Cause you think, God, maybe I'm doing something wrong. Maybe I'm not diapering her right. Maybe she's not comfortable laying like that. 'Cause everytime she's (nurse) there I feel like I have to ask, "do you guys want her laying on her back? Want her laying on her stomach? you know, how do you want me to lay her?" And I thought, I'll lay her any way I want to lay her.

Jacky:

> Like, depending on what night we went in there,...we had to bathe him, you know, seven different ways...some of them were so...like their way is the right way and that's that, like, never mind anything else you learned. Like instead of speaking with us and asking us how we felt or suggesting something, they would say, "Look, this is the way it's done and that's that".

Pam was able to achieve a measure of control over enforced routines. Ironically, she needed nursing assistance to realize that control.

> 'Cause when they changed his bath time again, we just got so that we would both be here at seven and bathe him and be done by seven-thirty or so, so they can feed him at eight, and well now they say "well, now we don't want you to do it until eight". But I had a good nurse on and she says to me "Well, forget that, you do what you can do, and the nurses can

> work around you". Which is right, 'cause we just got used to this you know,...she (nurse) made a point of educating me, just how to put our foot down and say "This is what's for us".

For the most part, there seemed to be a sort of tacit acceptance of the situation among the members of the study group. That is, that while the infant required care in the NICU, the mother's job was to cope; with rules and regulations, with personality conflicts, and with the negative interactions that were sometimes part of their relationships with the NICU nursing staff. Pam:

> And he's mine now, but he's not mine, because mine, I would be holding him all the time, I would be hugging him and loving him and you know I can't take him out so...I can stroke him, but whatever, I don't have a say, really, medically in what's going on with him. I can't change this, it's not like I'm in my own world and I can tell you to leave my house whoever you are, I can't do that so I have to just...I can't allow myself to resent it because that's the way it has to be...because when he gets home he'll be home and that's when I'll have my baby. Like right now, you guys need to do what you have to, I'm not going to fight that, but I know the difference.

Informants described themselves as having made concerted efforts to "keep the peace" in their relationships with the nursing staff. They found this emotionally exhausting at times, and had to find ways to deal with their frustrations. Pam:

> ...'cause I think sometimes it's 'cause I'm tired you know, I think I try and just be very positive and blame myself in thinking it's towards me...'cause I have to...if I was on the street I would have nothing to do with certain types of people in here, but that's me, I'm not generally, I don't like many types of people so it doesn't surprise me.

Jacky:

I am the type of person that would tell somebody what for without any hesitation but in there I never did. To the surprise of my husband. I'd go out and walk around. Go phone my Mom or something. Five hundred dollars later.

Mary:

Well, it is, it's exhausting... it just is you know, when you have to be...the nurses can be quite emotional too, they have their own personalities and they don't want to be ...I mean they're just questioned and hounded all day too by everybody, and I realize that but, it's, they kind of have to put up with me and I kind of have to put up with them...maybe even having to deal with people all the time that are ...I'm really worrying about their feelings, worrying about the nurses all the time and I'm tired of that too. Like trying to get along with everybody when I'm feeling so... I'm just, when I'm feeling so frustrated and stuff all the time, I just want to get back to the you know, worrying about the usual things like what we're gonna have for supper and not anybody's feelings and stuff.

Informants commented on a more ominous reason for keeping the peace and avoiding conflict. Sue:

...on one occasion when it (conflict) happened, I was absolutely devastated by it but rather than show the nurse how she had affected me on the off chance that it would jeopordize the care given to my baby I removed myself from the situation, and went elsewhere and sat down and had a damn good cry, because you know, all the tension that builds up from that kind of interaction has to come out somewhere.

Mary:

...those nurses are in charge you know, have to look after the baby and nobody wants to offend anyone that's looking after their baby, you know. I was like that with the doctors too, like I'll never talk back to Dr. "Z" or anything else because he just...they're human and I don't care if they...I know that they are professional and that they're not going to purposely, you know, not care for the baby the way that he should be taken care of, but still...nobody I know is going to take that risk.

On the whole, informants described themselves as feeling

more comfortable when civil relationships were maintained. For these mothers, things were "hard enough" and they therefore tried to "keep as much peace" as they could.

Trusting Professionals

The relationships that were developed between study subjects and the health care providers working in the NICU began with a certain sense of awe on the mother's part. Informants described feeling that they did not have the knowledge or expertise to have much input into the care given their infants. Despite their relative ignorance, it required a great deal of faith for informants to entrust virtual strangers with the total care of their newborn infants. In some cases, personality conflicts made trust more difficult. Sue:

> I mean you can talk to the nurses, you can talk to the doctors, but in terms of the actual medical care that is being given, it's out of your hands, and it's a very frightening thing, I mean you have to have a great faith in what's going on, a faith in the, the people who are handling your baby and there are times when the person who is handling your baby is not the one that you would have chosen to be taking care of him. Sometimes it's an outright dislike, I mean just like anywhere else in the world, in life, you don't get along with 100% of the people, and there are times when you're faced with the situation of watching someone you don't particularly like handle your baby in a way that you don't particularly like.

Pam:

> I just pray and realize that they're qualified and that they're trained...it's my problem that I don't like her, it's not that she won't be good or won't take good care of my baby.

In establishing trust, a perception of recognition, openness, honesty, and true caring on the part of

professionals was important to the study mothers. Mary:

> That's the way I feel about the doctor too. He's really shown quite a lot of interest in...he remembers things, you know he's got such a good memory...he knows when (husband) goes to work, he knows when he's going to be home, and he remembers things about my children, and he's said that he's really become quite fond of the baby, and it just really, I just trust him completely and it does make us feel 100% better. I really appreciate the feeling that the doctor shows towards us. You know, I don't know, and the same with the nurses actually, it's kind of, I guess it makes us trust them more...I have more trust in the ones that I think really, you know, have a true concern, not just a medical concern...

For Jacky, trust in the professionals caring for her baby grew as he progressed:

> I don't know, it just maybe it happens over time. Like he's getting better so they obviously cared for him the right way.

Communications

For study informants, communication with doctors and nurses about the infant constituted the bulk of their relationship with those professionals. Informants described a desire and a need to know about their baby, and the perception of openness and honesty in information sharing was crucial. Emily:

> I wanna know now, so I'll be over this and be strong later. You know, like this is garbage, the way it keeps dragging on and saying "she's going to be fine" and then I get home and something happens. If something's going to be like that, let me know now so I can get over this.

Mary:

> ...don't be cautious about what they tell the parents, because the nurses that would talk to me, I really liked them the best, the ones that would tell me every...as much as they could, those were the ones I liked. I have had a couple that were very, I

> mean they almost acted like it was a secret or something and I didn't like them that much.

When time was taken by professionals for communications which involved explanations of complicated conditions or treatments, informants felt reinforced in their role as mother. Mary:

> Actually, you know, I appreciate that somebody thinking that I, that there's a chance that I might grasp it, because some of the doctors won't even you know, say "boo" to you. Or tell you anything, so whether or not I understand it all was beside the point, the fact that he tried, you know, that he assumed that I might understand really was good. And I did basically understand it, but not to repeat it that well. But it gave me an understanding at the moment, you know, like what, you know what was happening.

Defensive reactions in response to mother's questions created confusion. Sue:

> Like, it's like hitting a person when they're down, if someone is in my situation, seeing something done to the baby, some procedure, and simply asking questions about it, and I am met with a very defensive attitude, it only confuses ...basically all parents are looking for is not explanations of the nurse's behavior but explanations of the procedures and sometimes they don't take it that way, you know, sometimes they respond in an agitative way, maybe they're having a bad day, everybody does, but in this situation, it kind of blow things all out of proportion.

Jacky:

> I feel totally dejected, like I'm, you know, am I this baby's mother or what, am I just, you know, here to observe or... it makes me feel like I'm not even a part of it.

Mary:

> I think that it's the whole thing that's confusing me, that on the one hand, these people are telling me to ask questions...ask questions they'll say, ask about everything, ask anything that you think of, I mean to the point where it doesn't even have to be

> something that you're concerned about if you're curious, ask...and on the other hand, there's people that have been really offended by it. I mean some of the nurses are too.

Nurses were not always perceived as helpful by the study mothers in providing information about the infant's health status. Instead, doctors were the final authority, with informants convinced that nurses sometimes withheld information awaiting a doctor's communication with the mother. Jacky:

> Usually I don't like, usually I want to come in and ask the nurses "oh what did the doctor say or anything" and they'd just say "oh well, he's doing fine", and stuff like that, they don't usually give you the details...somehow I like to hear it from the doctor better.

Pam:

> ....there was a nurse who was on last week and I said, "OK, what did the doctor say", 'cause I missed the visit. "Not much". OK, what did the doctors say, like I'm the type, I want the words and I'll tell you if it's much or not much, like I'll decide.

Informants spoke of their right as mothers to be informed about their infant's condition. They saw themselves as major stakeholders in their infant's outcome. Sue:

> I heard some parents who make suggestions or ask questions were told more or less to mind their own business. I prepared myself, I thought, if that particular individual ever responds to me that way, I'm going to ask them, whose business is it then since the child cannot speak for himself. This is my baby, I have the greatest stake in this baby's life...more than... you'll have him here for a week or a month or three months, I've got him for the rest of my life and whatever is going on here is my business and if I want it explained someone should be prepared to explain it, not tell me that it's not my business.

Mary:

> I know I'm not qualified and I don't want to interfere in that way, I really do make an effort not to interfere in that regard, but as long as I understand, because he's my baby and I want, you know, (to) protect him if I have to, or make sure that, I don't even know make sure of what, like it's not even that I could prevent anything, but I just want to know, I don't know why. I mean, even at school, you know, kids whose parents take a great interest in what they do the teachers focus on those kids, you know what I mean. And maybe in some kind of subconscious level in some way, maybe I think it's going to work in that way.

Relationships with other parents

Informants generally made few comments about their relationships with other parents of infants in the NICU. Opinion varied in the study group as to the benefit of the relationships that did exist. Sue, who because she remained in the hostel nearby her hospitalized newborn was separated for long periods of time from her family, described warm and supportive interactions with the other mothers.

> ...there's a comradarie amongst the other mothers, we all know each other by first name, I don't know half the last names here, but I know everybody by first name and we keep up to date on how we're doing, and take each other out to lunch or go shopping together, just to get out of here sometimes, just to have a shoulder to cry on, just to get through a critical time when one's own family can't be there. I find that talking with the other mothers is a tremendous help, we're quite close knit, we spend a tremendous amount of time talking, you know, trying to cheer each other up, doing things for each other...

Mary appreciated the special empathy that she felt only other mothers of preterm infants could possess:

> The only people that really give me any sense of help are the other mothers here 'cause I know that they are going through the same thing.

In contrast, Jacky scrupulously avoided mother to mother

discussions in the NICU, which she perceived as "contests" to tell the worst case story, contributing to her personal anxiety.

> Well, the worst thing that you could ever do is go into the pump room (breast pump room) and listen to everybody's problems. That's why I pump at home 'cause you go in there and somebody'll be saying "well, you know..." and then you wonder, whew, at least my baby didn't get that, (or) all in all, is this what's to come, or something. Like I find that, you know, that they depress each other more than....I say, you know, "how are you", "how's the baby doing" and stuff like that, I mean that's all there is in our lives right now...it helps to talk about it but still you wonder, oh no, is this what I'm in store for? Maybe I'm wrong in that but I feel like we should be cheering each other up instead of telling each other what could go wrong next. And that's the way it got, some of them were just, like I don't know whether they're sadists but it's like they thrived on if, if something else went wrong, you got more pity type of thing,...why would you want to drag yourself down like that, you just went further down the gutter.

Pam, on the other hand, said she found little time for interactions with other mothers as she rushed between home and hospital, attending to her various responsibilities.

On the whole, mothers whose infants were progressing well perceived fewer difficulties in their relationships with the professionals in the NICU. Anne, whose infant had a relatively uneventful neonatal course, consistently described an open, warm atmosphere in her interactions with professionals. Conversely, Mary, whose infant was very ill, experienced extreme frustration resulting from some of her interactions with professionals after being told that her infant's chart was "none of her business" and advised to "just look at the baby and never mind anything else". No

doubt, the anxieties and frustrations of both mothers and professionals had the potential to effect interactions in a negative way. The mother-professional relationship could become strained for a number of reasons regardless of the infant's health status. As mentioned, the study mothers expressed feelings that could be interpreted as an attitude of ownership of their preterm infant. It could be that conflicts between mothers and professionals arose over ownership issues. Regardless of the reason for conflict, it is clear that positive, supportive relationships between mothers and the professionals caring for their child were important to subjects as they continued in the process of forging a role.

Relationships at Home

The process of forging a role continued in the context of the relationships and responsibilities that informants held within their nuclear and extended families, and within an established social milieu outside the NICU.

The disruption in "normal" family life precipitated by the preterm birth and the events that followed had a negative effect on siblings, according to study mothers. Informants expressed guilt over their perceived lack of attention to siblings at home during the preterm infant's hospitalization. Mary:

> We have two other little kids at home too, four and six years, and it wasn't fair to them. We couldn't go on like that...we were trying to, you know, do things with the kids and spend time with the baby

> and take care of the kids at home too, like not to disrupt their schedule too much...the kids haven't been on time for school once since the baby was born I'm sure.

Because family routine was often so disrupted, informants were not surprised when siblings expressed their frustrations by acting out. The negative reactions of siblings seemed to raise the stress level overall for study mothers however. Mary:

> ...we're just treating him (sibling) the way we always do basically, I mean, trying to be as consistent as we can and setting the limits, and not trying to change too much stuff but, you can't do anything with him, he isn't responding to spanking, or he doesn't care what the punishment is, he doesn't care what it is...

Pam:

> My daughter does not want to have anything to do with him (preterm infant) now...so I'm going to, I was going to rent a (breast) pump but now I'm going to buy one, there's a battery-operated one, and I'm going to stay home with her, at least for this next week until this week coming, Monday to Friday, ...it's affecting us, she says we go to the hospital too much and she told one of the nurses she's sick and tired...which is cute, but it's the truth too, she is sick and tired, we all are, I mean it's hard coming here.

Two informants described some difficulty in their attempts to involve siblings with the hospitalized newborn. Pam:

> ...so I understand how much she's (sibling) hurting, it's very hard, last night she refused, she doesn't want to be around "D" at all, and that's understandable, but we are only with him for two hours in the evening, we're here, with the pump, we don't have to be here for so long 'cause it takes half an hour to pump, her good time would be half an hour and she gets restless, this past week it's "I don't want "D", I don't want to see "D"".

Mary:

> We brought them (siblings) down here so that they

> would know that really did have a little baby. They've been here three or four times I think. Quite a bit. It's harder to keep them down here so we kind of (make) a quick visit, especially my four year old.

Informants found it necessary to adapt their routine and the amount of their involvement with the preterm infant on an ongoing basis in order to meet the needs of others in the nuclear family group. Ultimately, family needs as a whole took priority, with study mothers devising a solution that was best for all concerned. Mary:

> I've got more of a routine now, I have a morning shift and a night shift, and the afternoon is for myself, well myself and mostly (sibling A)... (sibling B) doesn't get home from school 'til six, 'til four, so we, then we can have dinner together and then I go again (to the hospital) so. I tried nursing him (preterm infant) five times on Saturday and I think they could just wash the floor with me at the end of the day, like I was like a dishrag. That was too much, I think it won't work out, it won't work out with the kids either. But if I can keep it to these kind of two shifts, I think it'll be alright.

Pam:

> Now we're back to right, right where we should be. Now we are for (preterm infant) and (sibling). Now we're going to make it best for everyone, as best as we can. But, like, for the week I want to stay home during the day with (sibling), and have, do things, we could take her to a park and have some normality. And then we'll still come in the evening and that may not change her much, but it'll help.

The involvement of extended family members with the preterm infant was controlled by informants. Study mothers limited the amount of information given to these individuals and described several reasons for doing so. Emily selected the details she shared about her preterm twins in order to protect certain relatives:

> ...we just didn't tell them that they were so ill because it would just kill them...they are the first twins in 33 years so it's a big thing at home right now and to tell my grandmother something like that, like, she'd panic. You know, so we just didn't tell her. We figured that once they're out of the danger zone then we'll explain all the tubes and all that. All the other things that have been going on that we haven't been telling everybody because we didn't want to worry them.

Mary also withheld information selectively:

> I probably told my Dad the least, not because he couldn't handle it. It was because he couldn't understand it. Like he was too far away to ...I mostly just wanted to spare him a little bit. But he was told basically what the baby's chances were but I didn't go into detail or anything.

Pam shared details of her infant's condition, but only with a proviso:

> Just my family,...I've told "No comment back, unless it's positive, unless..." I mean, I know better now that, because initially I didn't know he was going to live, I don't need you going "ohhhhh, that's terrible, why is this happening, why is he having bradycardias". Because that's normal and I've explained and explained. Don't go like that anymore because it scares me. 'Cause then I get scared, I mean, I don't trust my instincts or...I have to go with what they (NICU staff) and... I've told my mother, "whatever I say, do not comment", because her comment sets me off to a panic.

Informants expressed the opinion that there was very little that extended family members could do to help the situation, and details of the infant's condition were sometimes withheld for this reason alone. When extended family involvement was kept limited, study mothers received less unsolicited advice, and felt freer to form their own opinions and make their own decisions, and thus they moved ahead in the process of forging a role.

Making the Break

The physical condition of all the study infants improved as time passed, albeit that the transition from intensive to convalescent care status took place within different time frames for each infant. The movement of their infant toward wellness was apparent to informants, and they began at this point to consider making a break from the NICU. Mary expressed some ambivalence initially about taking her son home:

> I am getting anxious to go home, but on the other hand I'm really afraid to take him home, I'm just going to be nervous about his breathing and those things. I'm not worried about the shunt or, you know, what's going to happen to him in the longterm is, ...just that first taking him home, I'm just worried about his breathing.

Informants began to visualize themselves in the role of primary caretaker at this point. Once technology was removed, this possibility seemed more realistic.

> 'Cause at first I realized, you know, that I couldn't do anything anyway, with all these...like it hurts to just go...all you could do is just stand there and look at her more or less, and you know, put your hand in and touch her hands or something, but it seemed like if she got a little better then I figured, well, I should be able to do that for her, especially after she got off her IV's and that.

Jacky:

> I don't like leaving at all. I feel like I can look after him now. I could stay here (in the NICU) and look after him, without, I don't need the nurses anymore.

Pam expressed the urgency felt by study mothers once they felt ready to take the infant home:

> I'm sure they were doing what they had to and everything, thay weren't holding him back, but to

> me, I felt they were and that he was ready...he was off his monitors, he was in a cot, and I thought he was going to get more infection being in the cot in their environment than in mine, my environment at home, 'cause there's all kinds of people coming...and I was going to get a lawyer, I was, that was it, that's all I felt, was that it was time and that's it. They didn't know I was going to get a lawyer, but that's how urgent, or how strong my feelings were.

At this time, informants described their preparations and plans for having the infant in the home. These preparations ranged from eliminating pets and smoking from the home, to installing humidifiers and sewing infant sleepers. Mary remained concerned about her infant having apneic spells at home, and on her own learned cardiopulmonary resuscitation and purchased a baby monitor. Pam planned to have her infant sleep in a cradle at her bedside for an indefinite length of time so she could "hear him breathing" at night. Sue described the alterations in her family's routine that would occur once her infant came home:

> In terms of his health, yes, we will make allowances, we will not take him to large crowds you know...and have people coming with colds, or anybody who smokes, or pets or paint things, or anything like that...I know what I'm going to face at home. I know we're going to be hermits for a year or so...

Jacky, in contrast, planned to quickly incorporate her preterm infant into the existing family lifestyle:

> (We're going on a) family holiday...(we'll) take him to the mountains his first weekend home.

Along with activities of preparation and planning, informants began to speculate about personal and family relationships with the preterm infant in the home. At this time, mothers also speculated on the preterm infant's

personality and future potential.

Informants described their confidence that the newborn would be well accepted by siblings in the home. They predicted a period of adjustment, which could be eased by positive input from mother and father. Sue:

> I mean it never is (easy) when you bring a new member into the family...but I'm sure they'll adjust well. They're very...very stable, they haven't been whining and crying and you know, having nightmares and wetting their bed because I'm not there...they have that, the years of growing up in a caring family.

Jacky:

> My daughter's like my husband, and she makes fun of anything that...doesn't make fun but if she notices anything that's different or out of place she probably will. But I think given the right family setting and the right explaining things to her that she would protect him. It's like, I'm one, like one of six children from my family and we fought like cats and dogs when we were in the house but as soon as we got out of the house, we protected each other, no matter what. I think it's the same type of thing.

In their speculations about the preterm infant's growth and development, two mothers expressed limited expectations.

Anne:

> I think maybe I expect her to be a little bit slower at things, at first, you know, maybe the first, well, even 'till school age maybe, I don't know. It's hard to say, I think it depends on, you know, her, herself, what she's going to be like. But right now I expect her to be a little slower, you know, walking and talking, all that type of stuff.

Jacky:

> I don't think that it will be that severe that he'll have to go, you know, be bussed to a different school, or anything like that, you know. He's not severely handicapped now, so I don't think it would be any gross situation like where he'll be different from the others. Maybe a bit slow or something...

Informants frequently speculated on how they would be most likely to mother their preterm infant in the home. As a group, they described themselves as likely to be overprotective towards the preterm infant, however, several mothers planned to make a conscious effort to avoid this, in the best interests of the child. Mary:

> Like if we're, if we're not going to let him learn how to walk because we're so afraid he might fall and hit his shunt or something, then, then he won't learn to walk. I mean we could slow him down by getting too worried about things like that. I'm assuming, like, nobody's told me that, but that would be, that's the kind of attitude that I have. I can see where if you just kind of acted on natural impulse you might tend to do that, but, I mean, I want to make a conscious effort to encourage him as much as I can to be independent and to grow and stuff.

Sue:

> ...in terms of his health, yes we'll make allowances, but in terms of his behavior, I would expect that we will treat him, as, like normal child.

At this time, subjects expected their fears for their infant's safety to persist in the home environment. They speculated on the possibilities. Pam:

> Is he going to have bradycardias at home, is he going to have apnea? We worried about apnea with my daughter...SIDS. I did, my friends don't, I'm the type that checked on her (sibling) all the time.

Mary:

> I know he won't be on the (cardiac) monitor at home and, and he does tend to do that (turn blue) when I'm feeding him. Of course, that should be, I'd have him right there so I could see him if it was but...you know, I don't know, I'm scared about what's going to happen to him at night too, when we're sleeping...as far as his care and what he's able to do, I will be scared in some ways, I'm not sure if I'll be able to sleep at night.

Despite their fears and concerns about potential problems in the home, study mothers were eager for their infant's discharge from the hospital. They did not express any feelings of personal inadequacy regarding their ability to care for their preterm infant on their own. At this point the informant's perception of herself as a competent, capable mother of a preterm infant was solidified to the extent that she eagerly anticipated the assumption of total responsibility for him in the home.

Mother at home-Role transition

The preterm infant's discharge from NICU represented a change for informants in their developing role as mother. A period of transition in the role began with this event, as mothers, for the first time, assumed total responsibility for their infant.

Informants experienced some ambivalence on the day of discharge. Mary:

> I think I could see that he was ready (to go home) too. Like he was just kind of waiting...and it seemed like that to me too. But even though...I say that I didn't really like it there (NICU) that much, you still get kind of attached to the place you know. (It was) a kind of strange feeling, you know I wasn't excited about it at all until half an hour before and I had to, quick, get ready and get, get him dressed and then I was practically hysterical, I wanted to cry, and I was just scared somebody would look at me, and that would be the end of it. I was really excited right before I came home but not at all until then. I don't know how to explain it, kind of, not annoyed, but like, I don't know, hard to explain. Not at all what you'd think. Like, now they're kicking me out, kind of thing.

Jacky:

I was scared to bring him home that day.

Fears and mixed feelings notwithstanding, for the study mothers, the positives in having the infant at home far outweighed the negatives.

With her son at home, Jacky quickly experienced a renewed sense of control and normalcy in family life.

> We're the ones that decide what happens to him and what...he's out of that atmosphere where he gets his diaper changed twelve different times, you know, during the day, and he gets six different techniques, it's different, that's the way it has to be in there, like without them he wouldn't be right, so you're so grateful to them, but on the other hand it's nice to get home and get back to our own routine too. When you're going into the hospital four times a day you can't, you don't have any, as soon as we got away from that hospital, like we were great. Well, then you have normality again.

Anne:

> But I find myself, my mood is better since she's been home. I used to break down in tears you know, I just wanted to go and see her, and I find since she's been home I'm a lot easier going, and not so snappy here. It's been easier on everybody. But it is a lot easier to deal with now that she is home, you can see for yourself that she, that everything is fine. You could see that when you went in there but it's not the same as being all the time.

Mary:

> We're really happy now. Really happy. I just was grinning so much yesterday and the day before my mouth hurts...it was so sore here, and I was by myself and I was just grinning at myself. I'm not nervous with, with the baby at all.

There were some residual effects of the monitoring that informants were subjected to as mothers of patients in the NICU. Mary:

> I still kind of catch myself, even here (at home). You know what I did, I take his temperature and

> wonder, what his head circumference is and stuff like that, and noticing if he's going to the bathroom, if they're wet, or not, and like things that I've, like perhaps getting to the point of counting voids and stuff, where I never did that with the other two. Like I feel like I'm kind of doing something I shouldn't be doing if I'm administering his vitamins, I need to ask if I can change his diaper and does anyone want to see if he peed or not, or...do you know what I mean?

In the home, informants seemed to need to get to know their infant all over again. They focused on infant cues and behavior, interpreting them. Emily:

> "D" hates being dirty. Oh God she hates being dirty but they (twins) hate being changed, 'cause they don't like being uncovered. So it's freak out every time you change their pants, they just go purple. And as soon as you get that tape or pin the diaper, they're done. They're calm.

Pam:

> He's just really good. Very quiet, but confusing because I don't know what he wants...he grunts and groans and whether that means gas or that he wants to nurse, and so he's fooling me a lot during the night 'cause I'm thinking he needs to nurse. And sometimes he just needs to be held for some reason, and that's enough, that'll get him over it, or we walk around with him to get the gas out...he's very gassy. But he seems, that's part of his grunting and groaning, and I guess that's what premi's do. Like all those faces and I, I was really concerned.

Mary:

> I don't know, he's a pretty calm baby still. He cries when he's hungry but he, he even has, like, he, it's almost like he's even trying, you know, to be a little patient or something, too. He's, he likes to be bathed and he likes to play and that. He's still pretty sleepy, he likes to sleep lots in between. But when he's awake, he's really awake, he wants to look around and, he loves to be talked to and stuff.

Anne:

> It seems like it, she doesn't cry hardly at all, the odd time. She'll sit in her little lounge chair and

> look around, last night she was awake for, oh, a good hour after she ate just looking around. One thing I noticed with her, I don't know if it's just, probably because she's not used to it, but she doesn't like to be held that much, just a little while and then she gets restless. Probably because she's not used to being held. She doesn't seem to be too fussy or anything. She's a good burper. And then you lay her down and she goes right to sleep.

Informants evaluated their infant's behavior based on what they had come to expect from a preterm infant. Emily:

> They (twins) respond. Like they're smart towards like when you go to those baby books you have to go back to the two month stage they're already doing. And I'm thinking to myself they were only supposed to be born on Tuesday so they're going to be a month behind. But they're not. Like they're picking up really good.

Mary:

> I was a little apprehensive because, well not really, because I thought what he was like in the hospital too, but I know that I've read a lot about premature babies and how they can be more difficult in some ways, I don't know, they get, maybe their digestive system isn't up to par as it could be, or you know, they tend to get colicky and things like that, but he's not any of those things, and his cry isn't really that high-pitched kind of scream I was reading about either.

The physical care of the infant was a primary concern for informants in the home environment. However, mothers made their own choices regarding that care, not without some uncertainty. Mary:

> ...and to bath, he really likes that, he doesn't like having his diaper changed very much though, I'm not sure why. Maybe it's the cotton balls that I use, like they keep the little bottle in the incubator (in NICU) and that used to keep it warm, but the little bottle that I keep on the dresser, I think the water gets kind of cold, maybe the water's cold on his bottom.

Anne chose to make variations in her previously established

infant feeding methods which were geared toward preterm infant needs:

> ...she likes to sleep a lot. Like a couple of times I've had to wake her up to feed her, you know, to keep her on three to four hours. One day, well, the first day she was home, she went five and a half hours, and I figured, seeing as she's this little she better not miss too many feeds.

Jacky, whose son had an asymptomatic patent ductus arterious also modified her usual child care routine with his needs in mind:

> Well, you know, he gets himself into such a tizzy (when crying), then he, you know, he goes purple, and, so you wonder you know, if there is anything wrong that maybe it's extra stress on, on whatever's wrong...and he cried so much that he doesn't have any air left and then you can just hear congestion, you know, and I keep thinking of his heart you know. But once you get the gold seal of approval (speaking to infant) you're up for it. Then you're really going to cry at night in your own bed. What a meanie, eh?

Interactions with Health Care Professionals in the Community

Informants described some difficulties in interactions with health care providers practicing in the community. Uncertainty or negativity on the part of these individuals hit study mothers hard during this period of role transition.

Pam was frightened and angered by the reaction of her pediatrician on her son's first office visit.

> We were doing very well because he was home, that's all I think us Mom's are waiting for, you get to the point where, well he's healthy now, or he's off the monitors or whatever, it's time to bring him home. And then we took him to the pediatrician and then he said, oh he was quite concerned about "D" being so premature, coming home so early, he was quite confused, 'cause the doctor at the hospital let him out. And then he said, "also he's (preterm infant)

> highly, he can catch infections quite easily right now...so we have to keep him bundled up like in the hospital with his hat on and everything. So we went back to being afraid again. First we were happy...and I don't like that. But he (doctor) sort of looked at me and said, "well he's home too soon, he's not even five pounds yet". And I should have said, "yes, but were you a mother, six weeks of going through times of being, coming home empty handed?", you know, like, you don't know...buddy.

That negative reaction led to renewed fear for Pam, and obviously shook the foundations of the confidence that she had so painstakingly built.

> I don't, right now I'm just trying to deal with it, trying to say, o.k., well prepare yourself if something happens but I don't want to...I don't want to, then so I'm sort of pulling back from (preterm infant) saying, well you know, I'm scared I'm going to lose him again so I'm pulling back and trying not to get too attached which isn't right.

Emily reacted to the comments of a public health nurse with anger, but remained confident in her own mothering ability.

> They sent me this Chinese lady and I almost opened the door and said, "could you leave?". Like give me a break lady. And I've had one (child) and I've got her for four years. I got them (twins) home. Don't bug me. She came I think the day after I got home and it's like, she held on to "C", no "D", she's holding "D" and it's like, "why aren't you breastfeeding?". And I think it's because they had the bottle so much that they don't want the boob. And they don't. Like they'll take breast milk but they won't take the boob. And she said something else and I said, "I know what I'm doing, you know". 'Cause they had their hats on because during the morning it's cool in here and I had just bathed them before she showed up I put their hats on in the morning or in the afternoon or whatever. After the baths I put their hats on because it is cool. "Well, if you have these hats on it's too hot". And I said, "They're not complaining". I said "if they complain I'll find the way to soothe them." I said, "I'll take their hats off, if they calm down fine. I'll take their sleepers off if they're too hot". And I said, "I don't care, she's my baby". These people drive me crazy because they think that you're so incompetent.

Family Involvement

According to study informants, siblings, for the most part, reacted positively to the preterm infant's homecoming. Anne:

> It didn't seem to bother them (siblings) though. Like, even when we went and picked her up (at the hospital) they were all excited, and taking, like, a peek in her bed all the time. If she's sitting in the chair here, they both have to climb up and kiss her...she's had so many kisses. (They) give her dolls to try and hold. They loved her. They didn't like it this morning when all those people (visitors) were holding her.

Jacky found that her five year old daughter could be helpful in the care of the preterm at home.

> Well, at suppertime she walks with him and, and he keeps quiet, like I just tell her to talk to him and she talks...sings her songs and...he's tired of "Material World", but...

Emily, on the other hand, experienced some difficulties with her four year old:

> Like (sibling) just, she's got to help and I understand and I understand that she feels left out. But like she's just more than I can handle sometimes. Lately she's been getting really cantankerous, like she just, she's got to push me to my limit. It's just going to take her a little time. And she's so quick (to pick the preterms up) you know. Like her father, she's too quick. You know and like you know she loves them, but she doesn't like them around.

Extended family members presented some problems for the study mothers once the preterm infant was at home. Informants tried to control the situation, focusing on a return to "normal" family life. Anne:

> ...Like I said before, I thought I would be possessive and that, you know, too many people handling her bothers me a little bit. Like this morning we had, well, my husband's sister came up

from Saskatchewan and a couple of her friends and her kids and they all passed her (preterm infant) around like, you know, and I said, "Enough, she has to go back to bed now." She's kind of a novelty, everybody's coming to see her, all the relatives.

Emily:

Yeah, it was hard the other day 'cause we went to see my Mom and like as soon as we walked in there it was like a stampede to the babies (preterm twins)...To my Mom I said, "you guys got to smarten up. Those babies are going to be here for the whole time you're visiting. Run to her (sibling) first. Make her (sibling) feel...", you know?

Mary:

I was thinking about it this morning, because like, even my aunt, she spent a lot of time up there (NICU) with the baby, and she wanted me to come over there and spend the night tonight (with the baby), and I really didn't want to, like, I thought it was just kind of foolish, you know, but like, he's not even my baby now, even with my family and stuff because everybody has gotten so emotionally involved, like, friends and stuff even, as soon as anyone finds out I'm here, they just have to rush over and see him, because he's kind of been in everybody's minds and things, you know. So, in a way, like, he isn't really totally mine, like the other ones, the more mine the better, like no one even wanted to babysit them or, or anything.

Coping with Disability - Questioning Normalcy

Since the preterm birth, concerns about the intellectual and physical normalcy and the potential disability of the infant were constant for informants. Jacky expressed the frustration that not knowing caused:

...we can't really do anything until we see, like we're scared to do anything, 'cause we don't know what he's going to be like, you know, it's like, you're, the thought entered my mind to ask the doctor whether, whether he knows if he's (preterm infant) going to be slow, or anything like that, but it's almost like I'm scared to...but it's such a stupid question I guess no one really knows. Nobody

> knows the answer, right? What can you do or say that...that leaves a lot of uncertainties about his development and stuff. Things that are inside his head instead of outside. Like, outwardly, he's actually doing very well, but it's the things that aren't tangible, you know, you can't see, and you can't really understand and that's kind of what's hard for us.

Mary:

> ...but we do worry about it (disability), but mostly because we want him to be as happy as he can be, you know, and all parents have high hopes and expectations for their children and I want him to have a good life, not just you know, stuck with me all of his life. I just want him so bad, and I feel like I can deal with actually, quite a bit of, of disability if I had to. Of course I might be, you know, I really don't know, I've never had to deal with it before but I don't feel like it would be a big problem for me.

Sue was optimistic:

> ...it's hard to tell, I mean, impossible to tell at this point what he's going to be like. But to my eye as a mother, he looks perfectly normal and if my husband were to ask me I would say, "he looks perfect to me." I'm realistic in that, you know, I know that there is still potential for there to have been some sort of damage, you know, possibly brain damage, or damage to a site, I mean, right now he's sort of an unknown entity, we don't really know what his potential is.

While their infant was still in the NICU, informants consistently monitored them for signs of normalcy, as they perceived them. Sue:

> He lifts his head, he can turn his head from side to side... his eyes are, they appear to both work simultaneously, which is encouraging...his sucking response started weeks back, and I thought that was a very encouraging sign.

Mary:

> ...he's alert when he's awake, and he follows,...he'll look at you, concentrates on you when you're talking to him and he can follow objects and you know, he learned how to nurse really easily,

like he's not really doing anything abnormal that I can see.

Once in the home environment, informants were optimistic about their ability to have a positive influence on their infant's growth and development. Study mothers coped with their uncertainty by reserving their judgment, and planned for ongoing professional monitoring of their infant by participating in follow-up programs and research studies. Mary's need to know about her infant was apparent:

> ...subconsciously, like you don't know what contributes to your development and growth and emotional development and so on, but, I think it probably will have, you can't say whether it'll be positive or negative, because you know, everybody's different in how they deal with things. Like, the fact that he was strong enough to want to fight and to, you know, survive the way he did makes me almost, you know, not assume that it's going to be negative automatically. Because I really think he's going to be fine, like already he's just not any different than the other kids when he was their age and, Dr. X. was telling that each milestone that he passes normally the better off he's going to be later so, like I just don't foresee any really major problems. I don't know if I mentioned that (research study) ...My husband was really apprehensive about that, and one of his arguments was that if there was something wrong, he didn't want to know, which it seems so stupid because I mean eventually it's going to show up, but if you wait until it shows up then it's more than likely too late to do anything about it you know.

Jacky:

> I think that deep down inside I know he's going to be alright, like, I do. I think he is. We'd like to keep in close contact with the (follow-up program) and doctors, and if there is a problem to find it, you know, soon so that we can get the best help for him...look at schools, et cetera. If you find it early you can lick it. Whereas, if (you) keep trying to ignore it and keep treating him as a normal baby, he might not, you know, he could get help, but he might not get help, the help that he needs.

Overall, mothers felt confident of their ability to cope and uncertainty about their infant's ultimate outcome did not seem to affect their commitment to their infant as mother. Jacky:

> So what if he has a little quirk or something, that's no big deal. I don't think that he's...I think that we can deal with it now, no matter what.

Reflections

At the final interview, informants spent some time reflecting on their experiences since the preterm birth occurred. At this time the study mothers were basically content and optimistic. Looking back however, there were positives and negatives for informants in their experiences.

Vivid impressions of their reactions to the NICU technology remained. Sue:

> I found it quite alarming initially, I know why they call the monitor's signalling systems alarms, it's because it's very alarming, you know, you see lights flashing and buzzers sounding and when it involves your own baby, it just is a wrenching experience, I mean like, I, on many occasions I thought I was going to need the CPR (cardiopulmonary resuscitation). It's a terrible thing to go through.

Jacky commented on the need, as a mother, to progress through the events. In retrospect, she was able to joke about what was extremely stressful at the time.

> Yeah, everybody has to go through it, you know, no matter what your background, or anything, when it's yours, you're, anything you know or experienced beforehand is nothing, 'cause when it's your own, you lose sense with anything that is, that you've been taught or anything. You just have to learn to deal with it and go through the progression. And I think we've got through that. We came across as lunatics, I'm sure. Childbirth does strange things

> to you. Well, it does, doesn't it? It changes your character totally.

The enviroment of the NICU was consistently stressful for informants. Once away from it, Jacky commented on her constant anticipation of disaster while her infant was in the NICU.

> I feel fairly confident that we're graduates of there. But it's a constant reminder while you're in there. It's like there's a mosquito flying around with AIDS and you have to keep slapping your body to make sure it doesn't bite you. That's what it's like in there. That's exactly what I felt like, like you know, there was one baby there on the corner, oh I betcha it's still there, baby G., it was there on the corner, like it was born way before Christmas and they just keep, you know, they're working on it constantly, all the time,...the father and the grandfather (of baby G.) came in and they (NICU staff) said, "look, the baby might not make it", and then two weeks later the baby pulled out of it and they (NICU staff) force-fed it with liquids and everything, and he's a big, bright, bouncy baby. And then they did hearing tests on it and they (parents) were told it was deaf. And then, you know what? A week before we left (the NICU), they (NICU staff) did another hearing test and the doctor came back and said, "well, maybe we did the hearing test too soon, she isn't totally deaf." So I mean, it's like you're sitting on your chair...and we got this result today...they (NICU staff) might change it tomorrow.

Mary described positive feelings about the way she had managed her infant's hospitalization.

> You know, like he really needed, I think he really needed me for that two months and I feel that it helped him to have me there. Like, who knows what would have happened if, you know, you think about other babies whose parents can't be there, or aren't there for whatever reason, and they just lay there day in and day out and a lot of them, it seems like they do just kind of deteriorate. They don't move on, and I don't know.

From a strictly clinical point of view, the experience had a positive outcome for all mothers in the study group. That

is, the preterm infants survived the neonatal period and were able to be discharged home to be with their families. Despite the outcome, feelings of regret about the preterm birth persisted for informants or their husbands. Mothers expressed these regrets at the final interview. Mary described her husband's continuing difficulty in assimilating the experience.

> (my husband has) more guilt than I do...he'll say, "gee, you know, you told me that you felt the baby dropped and why didn't I take you more seriously?", and you know, "why didn't I tell you to lay down, and when they told me you were in the hospital why didn't I just come down and supervise it myself?" like all these things that he could have done differently... I don't know, he said about a week ago, he said, " I think that this has just ruined my whole life." Like he just, it's really affected him...he (husband) is just quite single-minded anyways, because for me I still have, like to me, he (preterm infant) is here, so you know, I still have him and I have (husband), and we have a good marriage still and we still have the other two kids, like I certainly don't see it as the end of my life. I'm not saying that it hasn't changed, but it hasn't made it necessarily more gloomy, I wouldn't say. But his (husband) life is gloomy now, for a while anyway. He said he had just, you know, he's at work, he said, "no matter what I'm doing, if I'm sitting at dinner, or I'm at work or anytime that I'm just sitting anyplace I just can't stop thinking about him (preterm infant), and why did it have to happen to him." It's just really getting to him.

Jacky, in her reflections, expressed the feeling that she would have done things differently if she had had it to do over again.

> ...if I had been a stronger person I would have aborted the pregnancy. I just kept thinking, well I have two little blonde heads, I want, you know, there's another one in there, I can't do this. No, if I could do it over again, I wouldn't have went through the pregnancy. Not that I'm not grateful for (preterm infant), but I think it's just, like it could have turned out that, it could have turned out

> bad too...it could have been a very traumatic thing for the family.

Pam:

> Probably the worst is over. And it's...yeah it's over. Just fear, and now I wish,...'cause there's this lady who is down the block is the same term as me, same pregnancy, she's out to here now, I'm thinking, gee, look at how this lady across the street, her baby came to term and big, big baby...and you know, this guy's so little. So, now I'm wishing that I had stayed pregnant...

These feelings of regret may have been what led subjects to consider another pregnancy at this point, and all informants described having considered this, at least hypothetically. Hence, a desire to complete their childbearing experiences on a positive note seemed to exist for the study mothers. However, they feared repetition in the form of another preterm birth, and this fear had an influence on decision-making regarding future pregnancies. Pam imagined that subsequent pregnancies could turn out worse than that which she'd already experienced.

> No, if he lives, no (won't have anymore children). Right, if he lives, no because it seems I can't choose when he'll be born, the next child, it could be six months, and then to go through what those parents are going through there, that I know, in NICU.

To Sue, the idea of having more children seemed irrational but persisted nonetheless.

> ...you have such a tremendous sense of failure in delivering a baby prematurely, it's like you've only done half a job. Something has remained undone, and I think that's one of the reasons that I have been so busy trying to do things, I want to get something done to completion because I didn't do a good job with the baby. I even had the feeling a few weeks back, maybe I should have another one just to see that I can do it right, I mean, what an irrational

thought, but that's the way I was thinking.

Jacky:

> We're pretty lucky here, so why,...I feel pretty confident that it was the IUD that caused my problems and I think I could have a normal pregnancy again, as a matter of fact I'm totally convinced I could but I wouldn't go and get pregnant just to prove it...you probably learn to deal with whatever you're dealt, but I don't think I would do it, no, definitely not. If I got pregnant tomorrow I'd go abort.

Mary:

> I'd be willing to try (another pregnancy) but I'd be worried about it. And I don't know about worry-wart (husband), like it kind of goes back to the feeling like we didn't finish something or we didn't do something right, and he must be feeling the same thing too even though it wasn't his body you know. He's really got, it's almost like his delivery and everything. He's gone through the same things that I have and he feels like we didn't complete something because there was no way he wanted more children before he (preterm) was born and now, it's almost like he wants to, I don't know, prove that we can do it right...we did have two kids before but it is kind of an incomplete feeling like you didn't finish, here I was barely even six, just barely over six months.

In the final interviews subjects also commented on an increased sense of personal vulnerability that they felt as a result of their experience. Mary described how her outlook on life had changed:

> I can't hardly think of anything that could be worse except maybe having a live child die or, ...an older child, a child that you've gotten used to...being murdered by a rapist isn't very good either but I think it (the experience) does fit in those categories. And I've kind of changed in that regard that something did happen to me and now I'm not you know, this is going to sound really stupid, I shouldn't tell you this, but you know that silly killer that's been out, that's killed those two women and you think, you know, well, it was two of them, and you never think it'll happen to you, you know. And I don't have that feeling anymore. Like

that feeling is gone. Like I think anything can happen to me.

Pam:

It (experience) got me more into fear and to be afraid and not take this whole life, what's the word, not to take, laugh at life, not to think it's nothing, no big deal, and to realize how precious it is. And not to take it for granted, that's right.

Jacky;

You realize how precious they are, but then on the other hand, you can't be scared to let them cross the street alone either... you get, I think you get overly protective. Like, the whole two and one-half months in there (NICU) has made me a lot more cautious of my other children and what they do which is too bad... 'cause we're kind of free-spirit parents you know, we kind of let them do what they want to do but it has put a damper on it I think. But I think it'll wear off.

Mary:

...as far as (husband) goes, I don't know. He'll be, he's just, because this happened, and it's changed his life so much he's really a lot more, much closer to the other children too. Like he really appreciates them a lot more than he did before, really. We were going, we had it planned out how we were going to, just going to assimilate him (preterm) into the family and he wasn't going to make a ripple really, like I wasn't going to quit studying even for one day...like we just took him for granted already and he wasn't even here,...and he really whipped us into shape.

In this chapter, the process of forging a role was illustrated using selected comments of study informants. Similarities and differences in the steps of the process between individual subjects and for the study group as a whole were discussed.

The following chapter outlines the findings of the study and relates them to existing literature on the topics of maternal-infant attachment and role formation.

Implications for nursing and indications for future research arising from the study are also discussed.

Chapter V

DISCUSSION AND IMPLICATIONS

The purpose of this research was to discover, conceptualize, and describe mother's experiences of attachment to their newly born, hospitalized, preterm infants. Informant's perceptions of their relationship with their preterm infant at points in time, and over time, in addition to their descriptions of factors which affected this relationship were sought.

In this study report, the related terms of bonding and attachment are used. As mentioned, the term attachment was not defined prior to data cllection, but was assumed to have meaning for study informants. In speaking of their relationships with their preterm infants, study mothers used the term bonding, which was familiar to them, to refer to the formation of a postbirth relationship. The results of this research indicate that a maternal prebirth relationship with the unborn existed for study mothers. The process of forging a role provided mothers with access to the attachment process in the postpartum period, as they formed a role in relation to their preterm infant and thus were able to express their attachment relationship to him.

This chapter is comprised of three sections. The first presents a discussion of the basic social process of forging a role and its relevance for the evolution of the attachment relationship between a mother and her newly born,

hospitalized, preterm infant. In this section, a comparison between the information previously available in the literature on the topic of mother-preterm infant attachment relationships in the newborn period and the results of this investigative effort is made.

In the second section of this chapter a summary of some theories about role formation are presented. The process of forging a role is then discussed in light of this summary.

In the third and final section of this chapter, the implications of the findings of this study for the practice of nursing are discussed. Indications for future research arising from this investigation are also presented. Finally, the strengths and limitations of the study are detailed.

Forging a Role: A Basic Social Process

The process of forging a role was initiated by the study mothers in response to the event of preterm birth. In this study, the existence of the process itself was interpreted as both a representation and a continuing expression of the mother's attachment to her preterm infant.

Forging a role is best characterized as a series of successive steps, which are influenced by or are dependent on the occurence of certain conditions. The informant's progression through these steps ultimately resulted in the formation of a new role as mother of a preterm infant. A theoretical model for the process is presented in this section, and the relationships of the steps in the process

and influencing conditions are discussed and related to the information currently available in the literature.

Theoretical Model: Steps and Influencing Conditions

Initiation of the process of role formation

As stated, the process of forging a role was begun by the study mothers in response to the event of preterm birth. During the first interviews, informants commented on their prebirth relationship with their unborn, and through these comments indicated that an attachment or commitment to the child had developed during pregnancy. The study mothers repeatedly talked of behaviors during the prebirth period that could be identified as claiming (Rubin, 1975), and there was some evidence that this behavior persisted postbirth. For example, one informant described naming her daughter before birth, and knitting articles of clothing for her. Another recalled feelings of eager anticipation during her pregnancy, while still another took pleasure in the movements of her unborn twins in response to her external touch. This data supports the work of several investigators, for example, Cranley (1981), Leifer (1980), Rubin (1975), and Stainton (1985a, 1985b), who discuss mother's attachment or relationship to her child as beginning during pregnancy.

Mother's Initial Reactions

Feelings of shock, surprise, and fear were experienced by the study mothers following the preterm birth of their infant. The internal closeness the mother experienced with

her unborn during pregnancy was abruptly terminated and the baby was taken away from the mother physically. Study mothers were forced to give over to others the care of their infant at a time when mothers of fullterms protect their baby from others (Stainton, 1985b). Guilt, a unanimous emotion among the group, led informants to examine their own behavior in search of a cause for the preterm delivery. The reports of many authors (Benfield et al, 1976; Blackburn & Lowen, 1985; Harper et al, 1976; Jeffcoate et al, 1979; Jinadu et al, 1982; Lissenden & Ryan, 1982; Paludetto et al, 1981; Yu et al, 1981) detailing negative parental emotions in response to preterm birth are supported by the data obtained in this study.

Informant's negative feelings were a hinderance to them in the process of role formation, and at first they concentrated only on immediate concerns. At this time, the survival of the preterm infant was the primary focus, and informants tried to prepare themselves psychologically for the possibility of their infant's death.

Accepting

The attainment of physiologic stability was necessary for continued movement in the process of forging a role. That is, once the immediate survival of the infant was relatively certain, accepting as a step in forging a role assisted informants in "getting beyond" their negative emotions about the preterm birth of their infant. At first, accepting was characterized by the mother's recognition of

her own self-doubt, regret, and feelings of loss. As time passed, informants focused less on these feelings, however, a sense of chronic sadness about the birth and its consequences for the infant persisted. Accepting on the part of study subjects was dependent to a large extent on the mother's mobilization of support and emotional strength from previously established sources such as religious faith spouses, and positive family experiences. Decision-making and commitment to a routine regarding her involvement with her hospitalized preterm infant also helped each study mother to attain a certain sense of control over her own life and facilitated accepting.

Accepting was emotionally stressful for informants in that it required them to come to the realization that their current situation was not and could not be the same as in their previous childbirth experiences. Study mothers suffered a loss in terms of their expectations for a fullterm pregnancy and the birth of a healthy child, and initially had no basis for understanding what that loss would mean to them as a mother. Therefore, accepting was a crucial step in the process of forging a role for the study informants in that their ability to set their negative feelings aside allowed them to move towards increasing their personal involvement in mothering the preterm infant.

The negative reactions of parents to preterm birth are well documented in the literature and such literature is supported by the findings of this study. However, there were

no reports found which detailed a stage such as accepting, which, in this study, explained the way in which informants dealt with their feelings and moved ahead in the active process of role formation.

Involvement in Mothering the Preterm Infant

Beyond accepting, the process of forging a role was characterized by informants increasing their involvement in mothering the hospitalized preterm infant. Study mothers initially described their infant as unresponsive and were sensitive to and inhibited by perceived barriers to mothering created by life-saving technology.

Confidence and ease in touching and handling the preterm infant came only gradually to study informants. However, touch was an extremely important factor in the evolution of the maternal-infant relationship as mothers expanded their psychological commitment to their child to include the more "normal" interactions involved in caretaking.

Several factors influenced the informant's ability to become actively involved in the actual mothering of her hospitalized preterm infant. For instance, study informants typically tended to view themselves as helpless or useless in mothering the preterm infant and compared themselves unfavorably with their infant's current primary caretakers, the NICU nursing staff. However, it was evident that support and encouragement for the mother's involvement in her infant's plan for care positively influenced the process of

forging a role at this time. For example, informant's perceptions of warmth, sincerity, and true caring on the part of professionals set the stage for positive mother-professional interactions, and opened the door for informants to learn from them about mothering the preterm infant.

Depending on her infant's ongoing health status, the informant's belief in his ability to survive existed on a continuum between hope and despair. Consequently, the study mothers were reserved in their optimism concerning the preterm infant's ultimate outcome. This influenced forging a role in that signs of infant progress seemed to give informants the incentive and energy to continue, while signs of deterioration caused feelings of depression, a desire to escape, and conflicts in interactions with professional staff.

Problems relating to nuclear and extended family members besides the hospitalized preterm infant also influenced each informant's ability to become actively involved in a mothering role. Informants reported difficulties in scheduling time to meet the needs of all family members. Siblings were often less than enthusiastic about visiting the preterm infant in hospital, and acted-out at home in response to disrupted routines and limitations on their time with mother. Study informants also reported restricting the information given about the preterm infant to extended family members in order to maintain control over

unsolicited advice and to protect the feelings of certain relatives.

In the literature previously available on this particular topic, the degree of maternal involvement with the hospitalized preterm infant was examined primarily from an objective, etic perspective. The work of Minde et al (1978), which reported increased length and numbers of interactions between mothers and hospitalized preterm infants over time, and Minde et al (1983), which detailed relatively less frequent interactions between parents and their very ill hospitalized preterm infants compared to parents of well preterms, is indirectly supported by the findings of this study. That is, the results of this study indicate that maternal comfort and confidence in interaction with the preterm infant increase as time passes and with improvement in the infant's physical status. Investigations conducted from an etic perspective such as Daniels et al, 1984; Farnaroff et al, 1972; Marton et al, 1981; Minde et al, 1978; Minde, Marton, Manning, & Hines, 1980; Zeskind & Iacino, 1984, provide only speculation concerning the processes motivating maternal-infant interaction. These studies make no allowance for the effect of time constraints, family problems, or conflicts with professional staff on the mother's inclination or ability to become actively involved with her hospitalized preterm infant. In addition, while previous research has examined the interactive capabilties of the preterm infant as compared to

the fullterm infant (Brown & Bakeman, 1980; DiVitto & Goldberg, 1979; Field, 1977; Magyary, 1984), there has been minimal examination of the mother's subjective response to such decreased responsiveness.

It is apparent from the results of this study that many factors play a part in determining the quality and quantity of the mother's interactions with her hospitalized preterm newborn. Consequently, a direct association between visits to the NICU or length of mother-infant interactions while in the NICU, and maternal attachment or commitment, as has been previously suggested in the literature, is unlikely.

Establishment of a Caretaking Role as Mother of a Preterm Infant

All study informants were successful in their role development and eventually reached a point where they were comfortable and confident in their role as mother of a preterm infant. Study mothers may have used the terms comfort and confidence to mean competence in the care of the infant. It is not clear from the results of this study whether this feeling of confidence affected mother's abilities to read the cues of their preterm infants and thus provide appropriate care. However, the work of other investigators has suggested an association between high maternal confidence and suboptimal maternal-infant interactive patterns (Rovers & Fuller, 1986).

For informants, this comfort and confidence was achieved over time and occurred concurrently with the

infant's physical improvement from critical to convalescent status. At this point, study mothers were actively involved in feeding, diapering, and in social interactions with their preterm infants. In interviews, informants made statements such as "I can look after him now.", and "I should be able to do that for her.", and thus indicated a degree of readiness to break from the NICU. This readiness and the desire to remove the infant from the care of others indicated the mother's feeling of ownership of the infant. Mothers began at this time to speculate on family relationships with the infant in the home. Informants were optimistic about their ability to introduce the preterm infant into this environment with a minimum of difficulties, and described an increasing urgency in feelings of wanting to have the infant out of the hospital and at home, despite continuing concerns about sudden infant death syndrome, apenic spells, and infection once away from the protective environment of the NICU. No reports were found in the literature which examined the mother's psychological readiness to take her preterm infant home after a prolonged period of hospitalization. However, the results of this study indicate a strong desire on the part of informants to "take over" control for planning and providing care for the preterm infant.

Maternal Role Transition

The infant's discharge from the NICU led to further progress in the process of role formation. Once in the home

enviroment, the maternal role developed in relation to the hospitalized preterm infant underwent a transition. Instead of being subjected to external controls imposed by NICU routine, a technologically oriented environment, and standardized infant care practices, mothers were in control of infant care. Study informants described this transition as a welcome change, and reported that the situation in the home quickly returned to normalacy.

Feelings of regret about the preterm birth existed even at this point for study informants, although objectively, their experience had had a positive outcome. Informants indicated a lingering desire to complete their childbearing experiences on a positive note by considering another pregnancy. In addition, the study mothers described feelings of vulnerability to catastrophic experiences which had not existed prior to the preterm birth.

The personal experiences of mothers on having a recently discharged preterm infant in the home environment have not been previously documented in the literature. Instead, investigations have focused on more objective examinations of the mother-preterm infant relationship and interactions in the home (Choi, 1973; Jeffcoate et al, 1979; Jinadu et al, 1982; Leifer et al, 1972; Minde et al, 1983). A reliance on examination of the mother-preterm infant relationship from an etic perspective alone in the previous literature has done little to clarify the situation. The results of this study indicate that the mother is subjected

to challenges to her confidence in her role as mother through interactions with inexperienced community health care professionals. The effects of such challenges on the mother's ability to cope in the home environment are not known.

In summary, the process of forging a role provides a method for conceptualizing the way in which study informants developed and internalized a role for themselves as the mother of a preterm infant. Knowledge of and proficiency in such a role was necessary to study informants as they sought to continue the relationship to their newly born preterm infant that they had begun during pregnancy. The informant's active pursuit of the definition of this role and her ultimate participation in it served as an ongoing, outward expression of her attachment to her infant.

Formation of the Maternal Role

Role transition or acquisition has been described as a developmental or stepwise process in which the individual incumbent in a new role learns a set of norms for a particular social position. Factors such as prior knowledge of the expectations of a role as well as the clarity or degree of consensus associated with these expectations influence role acquisition. That is, explicit definitions of the behavior and attitudes expected in role performance ease the process of role acquisition (Burr, 1972; Thornton & Nardi, 1975). According to recently developed theories of role acquisition, individuals also impose their own

expectations and conceptions on a role, and psychological adjustment to a role occurs when the individual finalizes his own method of handling the social requirements of a role (Thornton & Nardi, 1975).

Relevant to this research, the maternal role has been defined as the acts that a mother is expected to perform in relation to her child. The behaviors and expectations within this role are thought to be acquired and culturally determined, and caregiving activities have been pinpointed as the primary maternal role functions (Chao, 1979; Mercer, 1985; Walker, Crain, & Thompson, 1986).

In this study, the process of formation of a maternal role in relation to a hospitalized, newly born, preterm infant was described. Informants were motivated to achieve formation of such a role as participation in the role provided for the continuance and development of the attachment relationship established with the preterm infant during pregnancy.

Four stages of role acquisition have been described in the literature. The first, or anticipatory stage accounts for the influence of prior knowledge of role expectations on role acquisition. Prior knowledge may be accurate or inaccurate, and therefore can be a benefit or a hinderance to role acquisition (Thornton & Nardi, 1975). In this study, informants had no experiential concept of a specific role as mother of a hospitalized preterm infant. Hence, it can be assumed that they were neither aided nor impeded by previous

knowledge in the process of role acquisition.

In the second, or formal stage of role acquisition, an understanding of the expectations or norms of a role are made explicit by the members of the role set and by the incumbent himself. In this stage there is an emphasis on consensus in expectations and on the conformity of the role incumbent to these expectations (Thornton & Nardi, 1975).

The informants in this study quickly perceived the potential differences between their new role and that which they had experienced with previous children. However, the expectations of the new role were not always made clear by the actors in the role set, that is, by the professionals working in the NICU. Consequently, mothers often felt frustrated and confused. Interestingly, while role expectations for informants were often inconsistently communicated by NICU staff, conformity to some of the role expectations such as unit routines and procedures was usually required.

During the third, or informal stage of role acquisition, role expectations are transmitted primarily through interactions, and at this point, the individual is free to shape the new role to fit himself (Thornton & Nardi, 1975). Study informants accepted the lack of consensus and clarity in expectations that they were met with and began to develop a method of maternal role enactment which best suited the needs of all their family members and their own personality. As previously mentioned, there was variation

among the study group as to the activities within the role, but each informant appeared to be "psychologically adjusted" to the role in that she was able to formulate and become comfortable with her own personal meaning for the role and its performance.

During the final, or personal stage of role acquisition, the individual imposes her own expectations on the role and modifies the role accordingly (Thornton & Nardi, 1975). As stated, study informants ultimately determined expectations for themselves in their role as the mother of a preterm infant. Their prior experience with the typical functions in the related role of mother of a fullterm infant formed the basis of these expectations, and study mothers consistently sought to become increasingly involved in the care of their preterm infant. Caretaking activities were adapted from those practiced by informants with previous, fullterm children to meet the constraints of hospitalization and infant illness, and special preterm infant needs.

Implications for Nursing

The findings of this research have implications for nursing practice with mothers and families of preterm infants. The actual and potential role of the NICU nurse requires examination based on the comments of the participants in this study. Informants easily described their perception of a "good" nurse, that is, one who

communicated an open, warm, supportive attitude and sought to involve the mother in the planning for care for her infant. "Good" nurses answered the mother's questions to the best of their ability and readily shared information with the mother. "Good" nurses were not necessarily clinical experts, but instead were those who seemed to the study informants to really care about the preterm infant.

"Bad" nurses, on the other hand, took a dogmatic approach to the care of the infant, and enforced routines without considering each mother's situation on an individual basis. "Bad" nurses also neglected to give mothers credit for having knowledge and experience in infant care, and communicated a closed, avoiding attitude in their interactions with study mothers.

Nurses who understand the process of forging a role could determine the progress of the mother and plan interventions accordingly. For example, a mother in the stage of accepting could best be assisted by providing empathetic understanding of her feelings of guilt and regret. On the other hand, mothers actively involved in the development of a caretaking role require the nurse's assistance to learn to care for their preterm infant. Mothers at this stage in the process would also benefit from the NICU nurse's support in planning for their infant's hospital discharge.

This model could also be used to determine whether mothers had reached appropriate stages in the process of

role formation at the time of the occurrence of specific events. For example, the infant's hospital discharge should coincide with the mother's readiness as well as with the infant's.

If nothing else, the comments of informants regarding their interactions with professional caregivers in the NICU, especially nurses, indicate the potential power and importance of these relationships. Nurses working with mothers of preterm infants must walk a fine line between the emanation of an attitude of confidence based on knowledge and clinical expertise, and an attitude which reinforces the mother's feelings of uselessness and helplessness in caring for her hospitalized preterm infant. Individualized, documented assessment of each mother's willingness and capability to become involved in planning and providing care for her preterm infant would give nurses a basis for establishing and continuing a working partnership with the mother during her infant's hospitalization. As is evident from the study results, involvement with caretaking of her infant facilitates the mother's role formation and provides an outlet for expression of her commitment to him.

The mother's contribution in terms of her awareness of her infant's patterns and responses to care should not be underestimated. As the mother is usually the one person who spends time with the infant on a consistent daily basis, she could potentially provide a vital information link, helping caregivers to bridge the information gap created by days

off, shift changes, and varying patient assignments.

Nurses must also be cognizant of the mother's need to come to grips with her loss in terms of a longed for term pregnancy and healthy newborn, and have sensitivity for the mother's feelings of personal guilt in the preterm birth. Awareness of the many additional pressures exerted on the mothers from sources outside the NICU environment should also lead nurses to assume a non-judgemental attitude in working with mothers of hospitalized preterm infants, avoiding the labelling of mothers or sets of parents as difficult or hysterical.

A most significant finding of this study is that a maternal prebirth commitment to the infant continues without interruption in the event of a preterm birth. As mentioned, previous literature suggests that interactions after birth are responsible for bond formation. An unfortunate extension of the thinking created by this literature is that events such as infant illness and maternal-infant separation are solely responsible for problems in the maternal-infant relationship <u>formation</u>. The results of this research indicate however, that the ongoing <u>development</u> of an existing maternal-preterm infant relationship can indeed be effected by events occurring after birth. However, these events have more to do with the mother's ability to develop and incorporate a role for herself as mother of a hospitalized preterm infant. Of importance to nurses as the primary professional caretakers of these infants is

consideration of their personal power and influence in teaching and empowering the mother in the development and incorporation of that role.

Indications for Future Research

Most significantly, an exploratory study such as this raises questions, provokes thinking, and indicates areas in need of further examination and clarification. The results of this study provide the stimulus for further research in several areas.

Informants selected for this study were successful multiparas. Each informant was also English-speaking, involved in a supportive relationship, and to a large extent, culturally familiar with the health care system. The success of these mothers in coping with the demands and expectations of their new role as mother of a preterm infant leads one to consider the relative chances for success in maternal role development for mothers of different cultural backgrounds or marital situations. For example:

1)What are the attachment experiences of single or adolescent mothers of preterm infants?

2)What are the effects of communication or cultural barriers on the process of role formation and hence on the attachment experience?

3)How are the experiences of a group of primiparas different from a multipara group?

4)What are the attachment experiences of mothers of preterm infants who have previously experienced neonatal death?

The informants for this study were interviewed only once at home after the preterm infant's discharge from hospital. In order to prepare mothers of preterm infants better for life outside the NICU, further study is required to document mothers ongoing concerns or any problems with the preterm infant in the home. Knowledge of problems encountered by mothers could be used to plan discharge teaching in the NICU and alternatives and solutions to problems identified at that time.

Research comparing groups of mothers of well hospitalized preterm newborns and mothers of critically ill newborns is necessary to determine the effect of the infant's medical status on role formation. The findings of this study suggest that mothers of very ill hospitalized preterm infants had more difficulties in their interactions with professionals. An attempt to clarify this finding should be made through further research.

Finally, replication of this study should be undertaken in different centers to account for the effect of unit-specific staffing and policies on the process of maternal role formation.

Strengths and Limitations

The sample selected for this study was well-suited for data collection on the topic of interest. Contributing to the consistencies in the process of role formation across the group were its homogeneous characteristics, such as multiparity, marital situation, fluency in English, and familiarity with Canadian/North American cultural norms. On the other hand, there was variation in the group in the level of education and in numbers of previous pregnancies, which undoubtably contributed to the broad range of data collected.

The investigator was responsible for all data collection and analysis and this contributed to the strength of the study in that a unique understanding of the situation at hand was developed. Familiarity with the clinical area of interest aided the investigator in understanding the medical terms and clinical situations which were so much a part of informant's comments and this understanding was automatically incorporated into the study report.

As stated, several mothers declined for personal reasons to participate in this research. It is not known what these reasons were, and consequently, the effect that such mother's responses would have had on study findings cannot be assessed.

Finally, one interview was conducted with each study informant after the infant's hospital discharge. This interview provided the information that the mother's role

was undergoing a transition. The ultimate outcome of this transition could only be known through further interviews in the home.

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APPENDIX A

CHARACTERISTICS OF THE STUDY SAMPLE

Table A-1 - CHARACTERISTICS OF SELECTED INFORMANTS

SUBJECT	AGE(years)	EDUCATION	MARITAL STATUS	OBSTETRICAL HISTORY	INTERVIEWS
1	27	GRADE 10	COMMON LAW	G3 P1 A1	3
2	32	SOME UNIVERSITY	MARRIED	G3 P2	4
3	26	SOME UNIVERSITY	MARRIED	G3 P2	4
4	37	GRADE 10	MARRIED	G8 P7	2
5	31	HIGH SCHOOL	MARRIED	G2 P1	3
6	36	UNIVERSITY GRADUATE	MARRIED	G4 P3	1

G = gravity

P = parity

Table A-2 - CHARACTERISTICS OF THE CURRENT PREGNANCY AND DELIVERY

SUBJECT	PP?	PROBLEMS?	S/M BIRTH	DELIVERY	GESTATION
1	YES	NONE	TWINS	CAESAREAN	34 WEEKS
2	NO	BLEEDING	SINGLE	VAGINAL	30 WEEKS
3	YES	NONE	SINGLE	VAGINAL	30 WEEKS
4	YES	PLACENTA PREVIA	SINGLE	CAESAREAN	33 WEEKS
5	NO	UTERINE POLYPS	SINGLE	VAGINAL	32 WEEKS
6	YES	BLEEDING	SINGLE	VAGINAL	26 WEEKS

PP? = PLANNED PREGNANCY

S/M = SINGLE/MULTIPLE PREGNANCY

Table A-3 - CHARACTERISTICS OF THE PRETERM INFANTS

INFANT	SEX	BIRTHWEIGHT	GESTATION	NEONATAL PROBLEMS	DISCHARGE
1(a)	FEMALE	2620gm	34 WEEKS	RDS. SURGERY	23 DAYS
1(b)	FEMALE	1850gm	34 WEEKS	THERMOREGULATION	23 DAYS
2	MALE	1130gm	30 WEEKS	APNEA. PDA	74 DAYS
3	MALE	1590gm	30 WEEKS	HMD. APNEA. IVH	57 DAYS
4	FEMALE	1790gm	33 WEEKS	RDS	26 DAYS
5	MALE	1410gm	32 WEEKS	APNEA	44 DAYS
6	MALE	760gm	26 WEEKS	RDS, BPD	109 DAYS

RDS = RESPIRATORY DISTRESS SYNDROME

HMD = HYALINE MEMBRANE DISEASE

BPD = BRONCHOPULMONARY DYSPLASIA

PDA = PATENT DUCTUS ARTERIOSUS

IVH = INTRAVENTRICULAR HEMORRHAGE

APPENDIX B

INFORMED CONSENT FORM

University of Alberta
Faculty of Nursing

INFORMED CONSENT FORM

Project Title: Maternal Attachment to the Preterm Infant
Investigator: Barbara Brady-Fryer R.N., B.Sc.

The purpose of this research project is to increase nurses understanding of how mothers describe attachment relationships with their preterm infants. At least four interviews will be conducted by the investigator which will last approximately 60-90 minutes each. During these interviews questions will be asked regarding your feelings about your relationship with your infant. Each interview will be taped by the investigator. The content of the tapes will not be shared with anyone, however, reports of the research containing anonymous quotations will be discussed on an ongoing basis with the investigator's thesis committee members. As well, a final report of the research project again containing anonymous information will be available to participants. There may be no direct benefits to participants of this study, but it is hoped that the knowledge gained in this study will improve nursing practice.

THIS IS TO CERTIFY THAT I, _____,
HEREBY AGREE TO PARTICIPATE AS A VOLUNTEER IN THE ABOVE NAMED PROJECT.

I understand that there will be no health risks to myself or my infant as a result of my participation in this research. I hereby give permission to be interviewed and for these interviews to be tape-recorded. I understand that the tapes will be erased at the completion of this research. I understand that my name will not be associated in any way with published accounts of this research. I understand that I am free to refuse to answer any specific questions of the investigator, and also that I am free to withdraw from the study at any time without penalty. I have had the opportunity to ask questions, and these questions have been answered to my satisfaction.

_____ _____ _____
PARTICIPANT WITNESS DATE

_____
INVESTIGATOR

APPENDIX C

SAMPLE GUIDING QUESTIONS

appropriate for the first interview

1) how are you feeling about the birth of your baby?
2) how do you feel about your baby being born earlier than expected?
3) how are you and the baby getting along?

appropriate for later interviews

1) how have things been going for you since we last met?
2) how are things between you and the baby?
3) how would you describe baby (as a person)? how do you know this about your child?
4) how do you see this baby fitting into the family?
5) how is this baby different (alike) your other children?
6) what things helped or hindered your getting to know your baby as a person?